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# A COMPARISON OF INTERDISCIPLINARY PALLIATIVE CARE TEAMS AND LEADERSHIP ATTITUDES OF NCI-DESIGNATED AND NON-NCI-DESIGNATED CANCER CENTERS IN THE UNITED STATES FROM 2009-2018

JOSEPH CHEN

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by

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DEDICATION

To My Family - Alfred, Evelyne, and Elizabeth

# A COMPARISON OF INTERDISCIPLINARY PALLIATIVE CARE TEAMS AND LEADERSHIP ATTITUDES OF NCI-DESIGNATED AND NON-NCI-DESIGNATED CANCER CENTERS IN THE UNITED STATES FROM 2009-2018

By

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DOCTOR OF PHILOSOPHY

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# PREFACE

I originally embarked on this journey for the pursuit of a career intersecting business and healthcare. Driving this personal quest was a desire to improve the quality of life of baby boomers in their later years of life, my parents and family friends included. While my classwork taught how best practices in Japanese automobile companies could be applied to reduce hospital errors, my work in palliative care at The University of Texas MD Anderson Cancer Center enriched my life perspectives by demonstrating that clinical research not only provides hope but also improves the quality of life for the living and those near the end of that walk.

ACKNOWLEDGEMENTS

I wish to thank my family for their unconditional love, support, and encouragement in the pursuit of this doctorate. I am thankful for the Department of Management, Policy, and Community Health and The University of Texas School of Public Health for taking a chance on me. I am thankful for the faculty who taught my classes, including Dr. Begley, Dr. Revere, Dr. Lairson, Dr. Mikhail, Dr. Krause, and Dr. Ganduglia-Cazaban. I am quite fortunate that many of my classmates became dear friends, sharing our diverse cultures and cuisines, unified in our goals to become experts in our respective fields. Furthermore, I am grateful for my employers – the Center for Healthcare Data – Trudy and Cecilia; my work with Dr. Rebecca Wells in restructuring the departmental website and editing a new version of a textbook; the Department of Palliative, Rehabilitation, and Integrative Medicine at The University of Texas MD Anderson Cancer Center – Dr. David Hui my PI, mentor, and friend; Janet Williams, my former manager; Julio Allo, my former director and friend for whom this would not have been possible; all my colleagues, but notably Allison de la Rosa in her instrumental efforts in administrating the surveys; my department chair Dr. Eduardo Bruera; and so many more! Thanks to Ariadne Reyes and Jhoanna Yuvienco for their friendship and support through the years. This dissertation would not have been possible without my committee members – Dr. David Hui, Dr. Paige Wermuth, Dr. Lee Revere, Dr. David Lairson, and Dr. Dejian Lai for agreeing to be on my A-team. Thank you Dr. Begley for advising me until your retirement and thank you Dr. Paige Wermuth for taking me in as your advisee and helping me navigate through to the end. Thanks to Dr. Shiva Dibaj, Dr. Shweta Pathak, and Dr. Shuangxi Ji for helping me with all my biostatistics and coding questions. A sincere and special thanks to Dr. David Hui for all the time he has put in to guide me with this dissertation from the conception of the study to the dissertation defense.

# A COMPARISON OF INTERDISCIPLINARY PALLIATIVE CARE TEAMS AND LEADERSHIP ATTITUDES OF NCI-DESIGNATED AND NON-NCI-DESIGNATED CANCER CENTERS IN THE UNITED STATES FROM 2009-2018

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## ABSTRACT

**Background**: Interdisciplinary palliative care (PC) teams (IDTs) are essential to improving patient outcomes while cancer center executives have a key role in defining the future of PC.

**Objectives**: To compare PC team compositions and executives' attitudes towards PC between NCI (National Cancer Institute)-designated cancer centers (NCI-CCs) and non-NCI-designated cancer centers (non-NCI-CCs) in 2018 and to compare changes in team composition and executives' attitudes and beliefs between 2009-2018.

**Methods**: PC program leaders (PL) and cancer center executives at all 62 NCI-CCs and a random sample of 60 of 1252 non-NCI-CCs were surveyed from April-August 2018. The PL survey examined team composition and certification requirements. The primary outcome was the presence of an IDT defined as a PC physician, nurse, and psychosocial member. Secondary outcomes were the size and number of individual disciplines. The executives' survey contained 12 questions examining attitudes towards PC integration, perceived barriers, and self-assessments. The primary outcome was agreement on the statement "a stronger integration of PC services into oncology practice will benefit patients at my institution."

**Results**: In 2018, 52/61 (85%) NCI-CCs and 27/38 (71%) non-NCI-CCs responded to the PL survey. NCI-CCs were more likely to have IDTs than non-NCI-CCs (92% vs. 67%; *P*=0.009). In contrast, non-NCI-CCs were more likely to have nurse-led teams (14.8% vs. 0.0%; *P*=0.01). The median number of disciplines did not differ between groups (NCI, 6.0; non-NCI, 5.0; *P*=0.08). Between 2009 and 2018, NCI-CCs and non-NCI-CCs saw increased proportions of centers with IDTs (NCI, 64.9% vs 92.0%, *P*<0.001; non-NCI, 40.0% vs. 66.7%; *P*=0.047). In 2018, 52/77 (68%) NCI-CCs and 88/126 (70%) non-NCI-CCs responded to the executives' survey. A vast majority of executives at NCI-CCs and non-NCI-CCs endorsed PC integration (89.7% vs 90.0%; *P*>0.999). NCI-CCs were more likely to endorse increasing funding for PC (52.5% vs 23.1%; *P*=0.01) and hiring physician specialists (70.0% vs 37.5%; *P*=0.004) than non-NCI-CCs. The top 3 perceived barriers among NCI-CCs and non-NCI-CCs were limited institutional budgets (57.9% vs 59.0%; *P*=0.92), poor reimbursements (55.3% vs 43.6%; *P*=0.31), and lack of adequately trained palliative care physicians and nurses (52.6% vs 43.6%; *P*=0.43). Both NCI-CCs and non-NCI-CCs favorably rated their PC services (89.7% vs 71.8%; *P*=0.04) with no major changes since 2009.

**Conclusion:** NCI-CCs were more likely to report having an IDT than non-NCI-CCs. Despite some growth over the past decade, there is further room for improvement for the PC workforce, particularly at non-NCI-CCs. Cancer center executives endorsed the integration of PC, with greater willingness to invest in PC among NCI-CCs. Resource limitations continue to be a major barrier.

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# BACKGROUND

## Literature Review

The National Coalition for Hospice and Palliative Care states that "[b]eneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family."[1] Palliative care is directed towards patients with chronic, complex, or life-threatening conditions[2] by providing symptom management but also focusing on hope, quality of life, and dignity.[3]

In addressing the holistic nature of palliative care, an interdisciplinary team (IDT) of physicians, advanced practice registered nurses, nurses, social workers, and chaplains coordinate continuity of care through the illness trajectory including during transitions of care and across settings. The most basic PC team consists of a physician and a nurse,[4] with team variations by setting. Although IDT members may be certified palliative care specialists in their own disciplines, their roles are to work with the patient and family to develop, implement, and update patient care plans to prepare for and treat physical, psychological, social, and spiritual needs."[5] Earlier integration with standard oncology care allows for preparation for unexpected rapid deteriorations in health, social functioning, and spiritual well-being. Key points of decline occur around diagnosis, after discharging from initial treatment, and illness progression to terminal stages.[6] Palliative care teams can range in size and discipline by setting.

## Palliative Care Integration

In 2010, a landmark randomized control trial examined the quality of life at baseline and at twelve weeks after newly diagnosed metastatic non-small-cell lung cancer patients were assigned either oncologic care or early palliative care with standard oncologic care. Significant improvements in quality of life and mood were found, measured by the Functional Assessment of Cancer Therapy-Lung (FACT-L) Scale and the Hospital Anxiety Depression Scale (HADS), respectively. Additionally, patients assigned early palliative care along with oncologic care received less aggressive end of care towards the end of life and longer survival[7].

Based on the findings by Temel and colleagues and other randomized clinical trials, the American Society of Clinical Oncology (ASCO) created the 2012 ASCO provisional clinical opinions (PCO) suggesting integration of palliative care into standard oncologic care.[8] In 2014, the WHO adopted a resolution that palliative care should be start after diagnosis and be integrated into care for individuals with terminally ill conditions.[9] In 2017's PCO, the ASCO Ad Hoc Palliative Care Expert Panel recommended that inpatients and outpatients with advanced cancer (distant metastases, late-stage disease, life-limiting, prognosis of 6-24 months) should receive dedicated palliative care early on. Additionally, the panel strongly recommends patients to be referred to interdisciplinary palliative care teams for consults and for newly diagnosed patients with advanced cancer to palliative care within 8 weeks of diagnosis.[10]

## Team Models in Healthcare

Teamwork is essential to effectively handle demanding caseloads. A team is defined as "a small number of people with complementary skills who are committed to a common purpose, set of performance goals, and approach for which they hold themselves mutually accountable."[11]

Patients with advanced incurables diseases face spiritual, physical, psychological, and existential challenges. It is difficult for a single provider to address all these needs adequately.[12]

Various models of teamwork exist and have been accepted in clinical practice: multidisciplinary, interdisciplinary, and transdisciplinary. In multidisciplinary teams, different team members evaluate patients independently according to their expertise[13] and assess, plan, and provide care with little to no involvement from the other team members.[14] Coordination is based on supervision or standardization and the team leader functions as a traditional manager.[15]

Interdisciplinary health-care teams can be described as "an identified collective in which members share common team goals and work interdependently in planning, problem-solving, decision-making, and implementing, and evaluating team-related tasks."[16] Interdisciplinary teams in palliative care are determined by the specific needs of the patient population being served.[14], Additionally, it involves collaboration and frequent communication among members.[17] Everyone is expected to coordinate their own activities and the team leader functions as a coach.[15]

A transdisciplinary team can be recognized by the blurring of or shared roles and responsibilities of its members. In this setting, team members' expertise may not be apparent to the patient or family members. However, the patients are able to obtain access to practitioners who have learned from other professions and may find a greater chance of a personality fit with a team member.[18] Ultimately, the goal is to provide care that aligns with the patient and family's preferences and values by utilizing the appropriate team model. Members can still maintain specialized roles but are prepared to replace one another when needed. Coordination is accomplished by close interactions and flexibility while the leadership is self-regulated and varies by situation and setting.[15]

The team makeup can be tailored to setting and patient illness complexity. For instance, at MD Anderson, both the outpatient ambulatory center and inpatient unit uses a team structure consisting of physicians, fellows, advanced practice nurses (APNs), counselor, social worker, physical and occupational therapists, nutritionist, and pharmacist. On the other hand, the mobile team consists of at least a physician, fellow, and APN [19]. In practice, a more multidisciplinary approach is applied in the outpatient setting at Anderson while a more interdisciplinary approach occurs in the inpatient PC unit. Patients in other inpatient units around the hospital seen by the mobile team can also request to be seen by social workers, chaplains, and other specialists.

**Interdisciplinary Teams in Palliative Care**

The complex needs of patients in advanced stages of disease cannot be sustainably and fully addressed by palliative care clinicians alone and require a team of trained specialists. The interdisciplinary team model appropriately assigns patient needs to specialists most capable of assisting the patient and the family. The frequent and shared communication among team members allow for effective and efficient delivery of patient care. Cancer care usually requires the knowledge base of specialty physicians such as medical oncologists, surgeons, radiation oncologists, as well as primary care physicians who provide an initial point of contact for screening and symptom evaluation [20].

In general, the interdisciplinary palliative care team consists of a doctor, nurse, and social worker, but team composition varies by setting and can additionally include advanced nurse practitioners, rehabilitation specialists, pharmacists, psychiatrists, dieticians, counselors, music and art therapists, and chaplains to holistically address symptom management, pain relief, and improve psychosocial difficulties and quality of life.

**Public Health Significance**

Around 78 million "Baby Boomers" in developed countries have entered a phase of their lives where heart disease, chronic diseases, and cancer are becoming more prevalent,[21] and will challenge the existing capacity of healthcare systems. The American Cancer Society estimates 1,762,450 new cases of cancer in 2019 and 606,880 cancer deaths based on 2002-2016 reported cancer deaths at the state and national levels reported to the National Center for Health Statistics.[22]

In the United States and other high-income countries, 75% of deaths stem from chronic diseases and can benefit from specialist or non-specialist palliative care.[23] This demand for palliative care is also met with a projected shortage of 6,000 to 18,000 palliative care specialists depending on time dedicated to hospice and palliative medicine.[24]

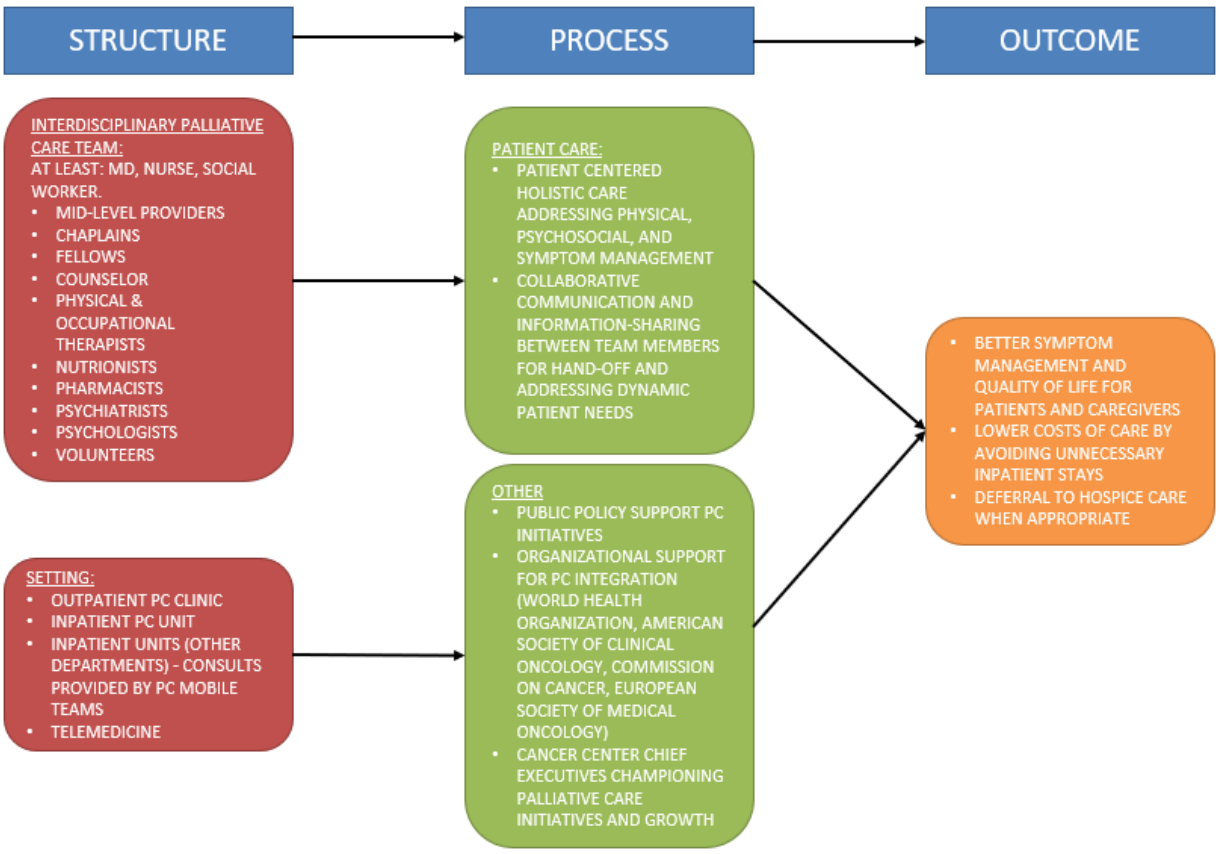
In consideration of the high per capita costs in the United States of $10,586 in 2018[25] and the Triple Aim Initiative (Better Care for Individuals, Better Health for Populations, Lower per Capita Costs), studies have found significant cost-savings associated with usage of palliative care services in both community-based and hospital outpatient clinics and inpatient units.[26-29]

The results of this study have implications for both policy and public health by identifying how cancer centers responded to ASCO guidelines one year after the 2017 recommendations were published. Additionally, the surveys assessed the attitudes and beliefs of executives who wield key decision-making power and can provide insight of what to expect in terms of palliative care growth in their respective cancer centers.

## Theoretical Framework

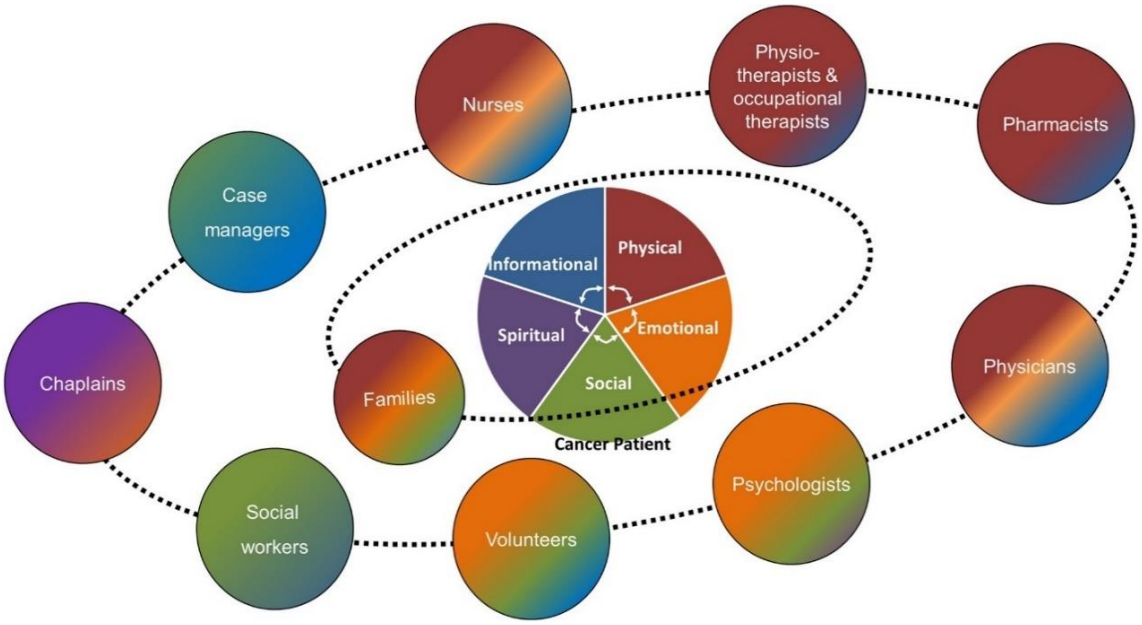
The theoretical framework derives from Donabedian's structure, process, and outcome framework in Figure A. The structure consists of both the interdisciplinary palliative care team and the setting. At a minimum, the interdisciplinary palliative care team includes a palliative care physician, nurse, and social worker in addition to a number of other allied health professionals or specialties. The setting varies from a supportive care outpatient clinic, palliative care inpatient unit, inpatient units in other departments consulted by the palliative care mobile team, and telemedicine visits. Process factors include those involving coordinated patient care, public policies supportive palliative care initiatives, organizational support for palliative care, and the support of cancer center executives. Outcomes pertain to cost-savings, deferrals to hospice care, and better symptom management for patients and caregivers.

**Figure A:** Theoretical Framework




The framework directly relating to interdisciplinary teams derives from a paper investigating the role teams play in delivering timely and multidimensional palliative care[30] in Figure B. In the interdisciplinary palliative care team, members share information with each other and provide holistic care to the patient and family according to their expertise, addressing physical, emotional, social, spiritual, and informational supportive care needs.

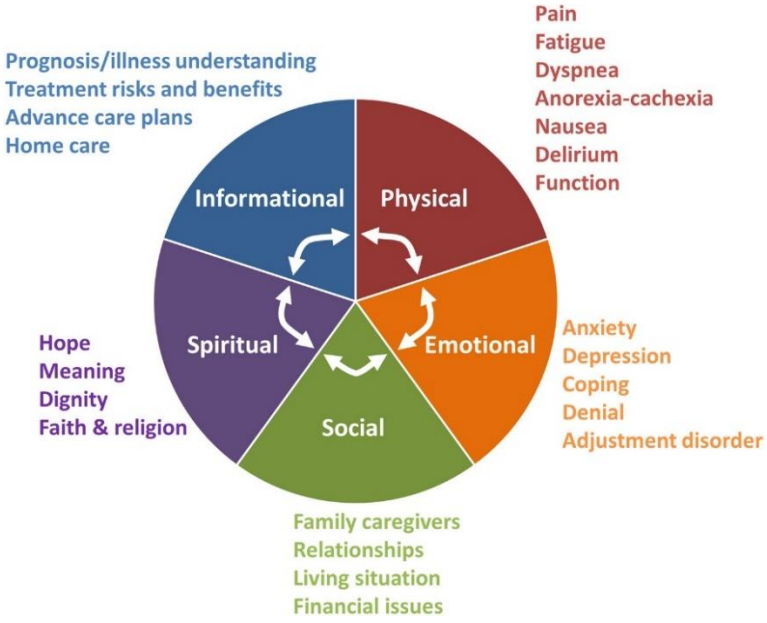
**Figure B:** The Interdisciplinary Palliative Care Teams. Adapted from Hui et al. *CA* 2018.




The color-coding and color-attributed spatial presence in circles representing IDT members and families in Figure B correspond to the multidimensional and interconnected supportive care needs, illustrated in Figure C. The dots connecting the team members represent shared communication.

Palliative Care IDT composition varies with healthcare setting and patient and family needs. The point in illness trajectory can also contribute to the team makeup, especially towards end-of-life care, but also early on.[31] In Figure C, the white arrows indicate multidirectional relationships in how changes in one dimension can influence other ones. For instance, a patient's increase in pain can affect his or her anxiety levels, increasing stress levels among family members and caregivers.

**Figure C:** Multidimensional Supportive Care Needs. Adapted from Hui et al. *CA* 2018.




## Specific Aims

### Article 1: A National Survey of Palliative Care Team Compositions

Article 1 will explore what proportion of cancer centers in the US have an interdisciplinary palliative care team, defined as a physician, nurse, and psychosocial member. It will also examine the team size, defined as the number of unique disciplines present in each cohort of cancer centers.

***Aim 1a***. To compare the palliative care team composition between NCI-designated and non-NCI-designated cancer centers in 2018.

***Aim 1b***. To compare palliative care team composition changes between 2009 and 2018.

**Article 2: Cancer Center Executives' Attitudes towards Palliative Care Integration**

Article 2 will primarily assess whether or not cancer center executives agree with the statement "a stronger integration of palliative care services into oncology practice will benefit patients at my institution." It will also examine barriers to access and self-assessments regarding palliative care.

***Aim 2a***. To compare cancer center executives' attitudes towards palliative care between National Cancer Institute-designated cancer centers and non-NCI-designated cancer centers in 2018.

***Aim 2b***. To compare changes in cancer center executives' attitudes towards palliative care between 2009 and 2018.

JOURNAL ARTICLE

**A National Survey of Palliative Care Team Compositions**

Journal of Pain and Symptom Management

## ABSTRACT

**Context**: Interdisciplinary palliative care teams are essential to improving patient outcomes. Objectives: To compare the palliative care team composition between NCI (National Cancer Institute)-designated and non-NCI-designated cancer centers in 2018 and to compare team composition changes between 2009 and 2018 cohorts.

**Methods**: Palliative care program leaders at all 62 NCI-designated cancer centers and a random sample of 60 of 1252 non-NCI-designated cancer centers were surveyed from April to August 2018. Questions examined team composition and certification requirements. The primary outcome was the presence of an interdisciplinary team defined as a palliative care physician, nurse, and psychosocial member. Secondary outcomes were the size and number of individual disciplines.

**Results**: In 2018, 52/61 (85%) NCI-designated and 27/38 (71%) non-NCI-designated cancer centers responded to the survey. NCI-designated cancer centers were more likely to have interdisciplinary teams than non-NCI designated cancer centers (92% vs. 67%; P=0.009). In contrast, non-NCI-designated cancer centers were more likely to have nurse-led teams (14.8% vs. 0.0%; P=0.01). The median number of disciplines did not differ between groups (NCI, 6.0; non-NCI, 5.0; P=0.08). Between 2009 and 2018, NCI-designated and non-NCI-designated cancer centers saw increased proportions of centers with interdisciplinary teams (NCI, 64.9% vs 92.0%, P<0.001; non-NCI, 40.0% vs. 66.7%; P=0.047).

**Conclusion**: NCI-designated cancer centers were more likely to report having an interdisciplinary palliative care than non-NCI-designated cancer centers. Despite some growth over the past decade, there is further room for improvement for the palliative care workforce, particularly at non-NCI-designated cancer centers.

## INTRODUCTION

Cancer patients experience a complex and multidimensional set of symptom burden.[1] While some of these challenges can be addressed through primary palliative care,[2,3] an interdisciplinary team-based approach better addresses the physical, emotional, social, spiritual, and informational needs[4] of patients and caregivers.[5] Randomized controlled trials have shown that specialized palliative care teams are crucial to improving patient outcomes.[6,7]

However, significant variation exists among palliative care teams regarding the composition of essential core members. Teams comprise of individuals representing a wide range of specialized skillsets: physicians, advanced nurse practitioners, clinic nurses, unit nurses, rehabilitation specialists, pharmacists, psychiatrists, psychologists, dieticians, counselors, social workers, music and art therapists, volunteers, and chaplains. Some studies have reported programs with only a single member, such as an advanced practice nurse,[8] to having teams consisting of multiple disciplines.[9-13] Interdisciplinary palliative care teams with a larger number of disciplines have been found to more effectively improve patient outcomes than a single disciplinary member,[4,8] and can more comprehensively address the multiple dimensions of care.

Currently, the proportion of cancer centers in the United States with an interdisciplinary palliative care team and corresponding team compositions is unknown. At the time of study design, the Commission on Cancer had accredited over 1,400 cancer programs, of which we

classified by National Cancer Institute (NCI) and non-NCI designation. The purpose of our study was to compare palliative care team compositions between NCI-designated and non-NCI-designated cancer centers in 2018 and changes in composition between 2009 and 2018.

A better understanding of the state of palliative care team compositions can provide program leaders and hospital administrators with key information to fill in structural gaps of palliative care programs and allocate appropriate resources to improve standards of care for cancer patients. An accurate national depiction of current palliative care team structures can help policy makers gauge progress and allocate resources to fulfill national and international recommendations on integrating palliative care into standard oncology care.

## MATERIALS AND METHODS

### Study Design

This was a prospective cross-sectional study, surveying program leaders from NCI-designated and non-NCI-designated cancer centers in the United States previously in 2009 and again in 2018. Survey questions were framed according to Donabedian's structure, process, and outcome[14] with question construction described in a previous study.[15] Program leaders, individuals identified as highly knowledgeable of their respective palliative care program and operations, were surveyed on aspects of palliative care, including services, personnel, certification requirements, referrals, education, and research. The 74 question 2009 survey served as the base for the 2018 survey, which included 8 additional questions on palliative care education and outpatient cancer patients for a total of 82 questions. Of the 82 question 2018 survey, 16 related directly to palliative care personnel, physician and nurse certifications, physician workload, and physician protected time were intended for analyses. The Institutional

Review Boards at the University of Texas MD Anderson Cancer Center and the University of Texas Health Science Center approved the study and granted exemption status.

**Survey Questions**

Respondents were asked to select the number or range of paid personnel assigned to palliative care: ward nurses (inpatient), clinic nurses (outpatient), chaplains, dieticians, mid-level providers (advanced nurse practitioners or physician assistants), palliative care physicians, rehabilitation specialists (physical therapists or occupational therapists), pharmacists, psychiatrists, psychologists or counselors, social workers, and other. Answer choices for clinic and ward nurses were 0, 1-5, 6-10, 11-25, 26-50, and more than 50. For all other personnel, the answer categories were 0, 1, 2-5, 6-10, and more than 10. Additionally, program leaders were asked to state the number of full-time equivalent physician positions available in the palliative care program, the number of physicians with at least 20% academic protected time, whether palliative care physicians are required to be certified by the American Board of Hospice and Palliative Medicine or American Board of Medical Specialists, and if palliative care program nurses are required to be certified by the National Board for Certification of Hospice and Palliative Nurses.

**Survey Population**

All cancer centers in this study were accredited by and obtained from the Commission on Cancer database. Accreditation requires compliance with the American College of Surgeon's *Optimal Resources for Cancer Care*,[16,17] a standards guideline for patient care, quality improvement, education, and research. We further categorized centers as NCI-designated or non-NCI-designated. NCI centers are celebrated as scientific research leaders that recruit heavily for

clinical trials, are affiliated with university medical centers, emphasize training and education, deliver leading-edge treatments, and meet rigorous standards for the prevention, diagnosis, and treatment of cancer.[18] Moreover, the vast majority of cancer care in the United States is provided collectively by non-NCI-designated cancer centers that are typically smaller and experience a lower patient volume individually.

Survey responses were categorized by year and NCI-designation status. There were a total of 6 cohorts: 2009 NCI, 2009 non-NCI, 2018 NCI previous, 2018 non-NCI previous, 2018 NCI current, and 2018 Non-NCI current. 2018 "previous" cohorts were centers surveyed in 2009 that were resampled in 2018. 2018 "current" cohorts were newly sampled cancer centers. At the time of survey administration in 2009, we identified 71 NCI-designated cancer centers and 1,411 non-NCI-designated cancer centers in the Commission on Cancer database. In 2018, there were 62 NCI-designated and 1,252 non-NCI-designated cancer centers. The sampling methodology is described in further detail in our 2020 publication.[19]

**Data Collection**

Our research staff contacted every cancer center by phone after internet search to confirm whether a palliative care program existed and inquired for the appropriate program leader to survey. Each program leader was mailed an invitation, a paper copy of the survey with a prepaid envelope, and a $10 gift card regardless of participation. A secure electronic survey option (https://www.qualtrics.com) was provided as an alternative. Follow-up letters were sent at 2 and 4 weeks while emails and phone calls were made at 8 weeks. All data collection occurred between April and August of 2018.

**Statistical Analysis**

The primary and secondary outcome variables were coded separately from the original survey questions and all ordinal variable responses were converted to binary format. The primary outcome was an interdisciplinary palliative care team, defined as a palliative care physician, nurse, and psychosocial member.[10,11] Nurses, as part of the interdisciplinary team, included either unit nurses, clinic nurses, advanced practice nurses, or physician assistants. A psychosocial member, as part of the interdisciplinary team, included either a chaplain, social worker, psychologist, or psychiatrist. The secondary outcome was the team size, measured by the total number of cited disciplines by center with a maximum of 12 from the survey. Exploratory analyses were conducted after generating new variables to obtain the proportion of centers with at least a nurse and no palliative care physicians, the proportion of centers with a palliative care physician and no nurses, and teams with only a nurse and physician. In these additional analyses, a "nurse" was defined identically as for the interdisciplinary palliative care team.

Data analyses were performed using SAS Version 9.4 for Windows 10 and IBM SPSS Statistics for Windows, version 24 (IBM Corp. Armonk, N.Y., USA). Descriptive statistics were generated for variables to obtain proportions, medians, and interquartile ranges (IQR). Visualizations were created with DataWrapper (Berlin Prenzlauer Berg, Germany). Fisher's Exact and Chi-Square test were used to obtain *p* values for the primary comparison between the 2018 NCI current and 2018 non-NCI current cohorts. Logistic regression via generalized estimating equations (GEE) were used to compare cohorts with overlapping (partially matched) cohorts while logistic regression was used to compare non-overlapping (unmatched) cohorts to generate odds ratios (OR), 95% confidence intervals (CI), and *p* values. Secondary comparisons involved 2009 cohorts and a current sample in 2018: 2009 NCI vs 2018 NCI current (partially

matched), and 2009 non-NCI vs 2018 non-NCI current (unmatched). Exploratory comparisons involved the 2009 cohort which was resurveyed in 2018: 2009 NCI vs 2018 NCI previous (matched); and 2009 non-NCI vs 2018 non-NCI previous (partially matched). Continuous outcome variables with skewed data distributions were converted into binary format for analysis by GEE logistic regression or traditional logistic regression while those that were normally distributed outcomes were evaluated via general linear models by GEE. The significance of primary outcome was evaluated with a *p* value less than 0.05 while the other analyses were considered hypothesis generating.

## RESULTS

### Survey Response Rates

Methodology for response rate calculations were derived from the 2016 definitions by the American Association for Public Opinion Research.[20] The program leader survey had an overall response rate of 75% (123/164). Of these, 61/76 (80%) of NCI-designated cancer centers responded while 62/88 (71%) of non-NCI-designated cancer centers completed the survey. No significant difference was found among states for the randomly selected 2018 non-NCI current cohort (*P*=0.35). This review was inapplicable to NCI-designated cancer centers since all were sampled. Additionally, the differential between NCI-designated and non-NCI-designated cancer center response rate was found to be insignificant (*P*=0.21).

### Palliative Care Teams: NCI-designated and Non-NCI-designated Cancer Centers

The primary outcome was a statistically significant difference in reported interdisciplinary palliative care teams between the 2018 NCI current and 2018 non-NCI current cohorts. The NCI

current cohort, compared to the 2018 non-NCI current cohort, was more likely to report an interdisciplinary palliative care team consisting of a physician, nurse, and psychosocial member (92.0% vs. 66.7%; *P*=0.009), a palliative care team consisting of a nurse and physician (98.0% vs. 74.1%; *P*=0.002), a clinic nurse (83.3% vs 52.2%; *P*=0.006), a palliative care physician (100% vs. 84.0%; *P*<0.001), full-time equivalent physician positions in palliative care (median 4.0 vs 1.0; *P*<0.001), and number of palliative care physicians with 20% protected academic time (median 2.0 vs 0.0; *P*=0.007), and physician certification requirements for palliative care (94.1% vs 59.3%; *P*<0.001). The 2018 non-NCI current cohort was more likely to have a team consisting of at least a nurse and no palliative care physicians (0% vs 14.8%; *P*=0.01).

**Current Cohorts**

In 2018, we surveyed all NCI-designated cancer centers at the time as well as an approximate number of randomly sampled non-NCI-designated cancer centers. The 2018 NCI-designated cancer centers, compared to 2009 NCI-designated cancer centers, were more likely to report an interdisciplinary palliative care team (92.0% vs 64.9%; *P*<0.001), a psychosocial team member (93.9% vs 81.8%; *P*=0.048), a clinic nurse (83.3% vs 48.8%; *P*<0.001), a chaplain (80.9% vs 55.1%; *P*=0.01), requirement for physicians to be certified (94.1% vs. 58.6%; *P*<0.001), number of physicians with at least 20% protected academic time (70.0% vs 41.8%; median 2.0 vs 1.0; *P*=0.006) and total number of disciplines represented in the palliative care team (median 4.0 vs 1.0; *P*<0.0001).

Compared to 2009 non-NCI-designated cancer centers, 2018 non-NCI-designated cancer centers were more likely to report an interdisciplinary palliative care team (66.7% vs 40.0%;

*P*=0.047), a psychosocial member (95.8% vs 64.0%; *P*=0.02), a social worker (91.7% vs 54.5%; *P*=0.009), and a larger number of disciplines (median 5.0 vs 3.0; *P*=0.04).

**Previous Cohorts**

The 2009 NCI-designated and non-NCI-designated cancer centers were resurveyed in 2018 and responses were compared. The 2018 NCI current cohort, compared to the 2009 NCI cohort, was more likely to report an interdisciplinary palliative care team (86.5% vs 64.9%, *P*=0.002), a psychosocial member (91.8% vs 81.8%; *P*=0.04), a clinic nurse (83.3% vs 48.8%; *P*<0.001), a chaplain (80.4% vs 55.1%; *P*=0.005), physician certification requirements (86.5% vs 58.6%; *P*=0.004), and larger number of disciplines (median 6.0 vs 4.0; *P*<0.001).

The 2018 non-NCI current cohort, compared to the 2009 non-NCI cohort, was more likely to have an interdisciplinary palliative care team (64.7% vs 40.0%; *P*=0.01), a psychosocial member (96.6% vs. 64.0%; *P*=0.01), a certification requirement for physicians (74.2% vs 50.0%; *P*=0.049), and full-time equivalent physician positions in palliative care (93.9% vs 68.8%; *P*=0.02).

**DISCUSSION**

In this national survey, we found that NCI-designated cancer centers were more likely to have interdisciplinary palliative care teams while non-NCI-designated cancer centers were more likely to report having nurse-led palliative care teams without physicians. Although the number of cancer centers with interdisciplinary palliative care teams has grown over the past decade, our survey highlights that major gaps remain in the structure of palliative care teams, and that administrators need more resources to provide more comprehensive team-based palliative care.

We found that interdisciplinary teams were missing from one-third of non-NCI-designated cancer centers. The absence of interdisciplinary teams from non-NCI-designated cancer centers mainly stemmed from a lack of palliative care physicians in 1 of 6 non-NCI-designated cancer centers, as nurses and psychosocial members were both present in over 95% of the non-NCI-designated cancer centers surveyed. Our finding is concerning because non-NCI-designated centers treat the majority of cancer patients in the United States.[5] The current training capacity of US palliative care physicians is already insufficient given the projected population growth and demand for palliative care.[21] Furthermore, having an interdisciplinary team is an indicator of integration.[22] The lack of physicians may be a marker for limited institutional investment in palliative care. Thus, it is important to not only mandate interdisciplinary teams as a minimum requirement for palliative care programs similar to hospices, but to also create training opportunities to staff the interdisciplinary palliative care workforce,[23] and to invest adequate resources to support more patients who can benefit from palliative care.

This study also found that nurse-led palliative care programs with limited or no physician involvement were more common at non-NCI-designated cancer centers. Palliative care nurses include hospice nurses, advanced practice nurses with a master's degree or higher, or acute care registered nurses with further training.[24] Nurses educate, advise, and provide emotional support to patients and families while coordinating with multidisciplinary teams to provide holistic patient-centered care in a cost-effective manner.[25] However, physicians are considered essential members of an interdisciplinary palliative care team because they have specialized expertise in symptom management and prescription authority. They are also actively involved in promoting prognostic understanding to facilitate complex decision-making around cancer treatments and care planning. Randomized controlled trials have found improved outcomes with

interdisciplinary teams but uncertain benefits for nurse-led or nurse-only palliative care provision. For instance, a randomized clinical trial examining very limited consultation provided by a palliative care nurse found no improved outcomes compared to standard oncologic care alone.[26] Although nurses are less costly, they can only provide care consistent within the scope of nursing and other disciplines are needed to ensure comprehensive holistic care can be provided. Policy makers can justify the cost-savings associated with palliative care services additional to improved quality of life and survivorship with advancing state and federal agendas. Further research is also needed to determine how to tailor palliative care teams to specific settings. For example, nurse-led programs may be appropriate for patients in some circumstances. As telehealth becomes more common due to COVID-19, there will a need to further develop virtual teams,[27] which would also increase patient access to interdisciplinary palliative care teams, especially for areas with limited resources.

We also noted a similarity in team sizes between NCI-designated and non-NCI-designated cancer centers, with reports of 5-6 disciplines each. Palliative care teams regularly comprised of clinical personnel, but also frequently included psychosocial members. In fact, social workers and chaplains were among the most reported professions in both NCI-designated and non-NCI-designated cancer centers. Social workers provide emotional and social support, handle case management, and interpret and navigate the healthcare system.[28] Chaplains build and nurture relationships, provide care in the time preceding death, and alleviate spiritual distress.[29] The high proportions of centers with psychosocial members suggests that administrators recognize their relevance in palliative care teams.

Several of the least reported disciplines in NCI-designated and non-NCI-designated cancer centers were dieticians, rehabilitation specialists, and psychiatrists. Dieticians tailor

nutritional plans for patients according to their needs and emphasized the need for specialist-level dietary education.[30] A previous study found that dieticians expressed concerns of their generally unrecognized role in palliative care.[31] Rehabilitation specialists enable patients to preserve function and independence. Psychiatrists have specialized expertise in the management of depression, anxiety, delirium, and other mental illnesses, a skillset that can be complementary to that of other palliative care specialists.[32] The absence of these and other disciplines could be from reasons including but not limited to prioritizations in hiring, budgetary restrictions, and or an incomplete understanding of specialists' importance to the palliative care team. Moreover, patients can benefit from the assimilation of less common disciplines into the interdisciplinary team rather than from non-palliative-affiliated consultations because of the information-sharing and collaborative nature.

Over the last decade, NCI-designated cancer centers grew by proportion and team size, in addition to experiencing increases in clinic nurses and chaplains. These changes were not surprising given the generally better access to resources, larger patient volumes by institution, increased academic affiliations, and willingness for leadership to invest in evidence-based models of care. Despite many positive changes, NCI-designated cancer centers can still improve by assessing each site and consider expanding teams to include additional disciplines that could benefit patients.

Similar to NCI-designated cancer centers, non-NCI-designated cancer centers also experienced growth in the form of greater proportions of centers with interdisciplinary teams, increased clinic nurses, social workers, and larger team sizes over the last 10 years. The results are particularly encouraging since a larger proportion of cancer patients are seen at non-NCI-designated cancer centers as a whole, whereas NCI-designated cancer centers typically see more

patients by site. The emphasis of nurse-led teams among non-NCI-designated cancer centers was supported by a decreased percentage of palliative care physicians over the same time period, while the proportion of centers with unit nurses, clinic nurses, and mid-level providers increased. Palliative care growth in NCI-designated and non-NCI-designated cancer centers over the past decade was in alignment with cancer center leadership attitudes towards increasing palliative care funding.[15]

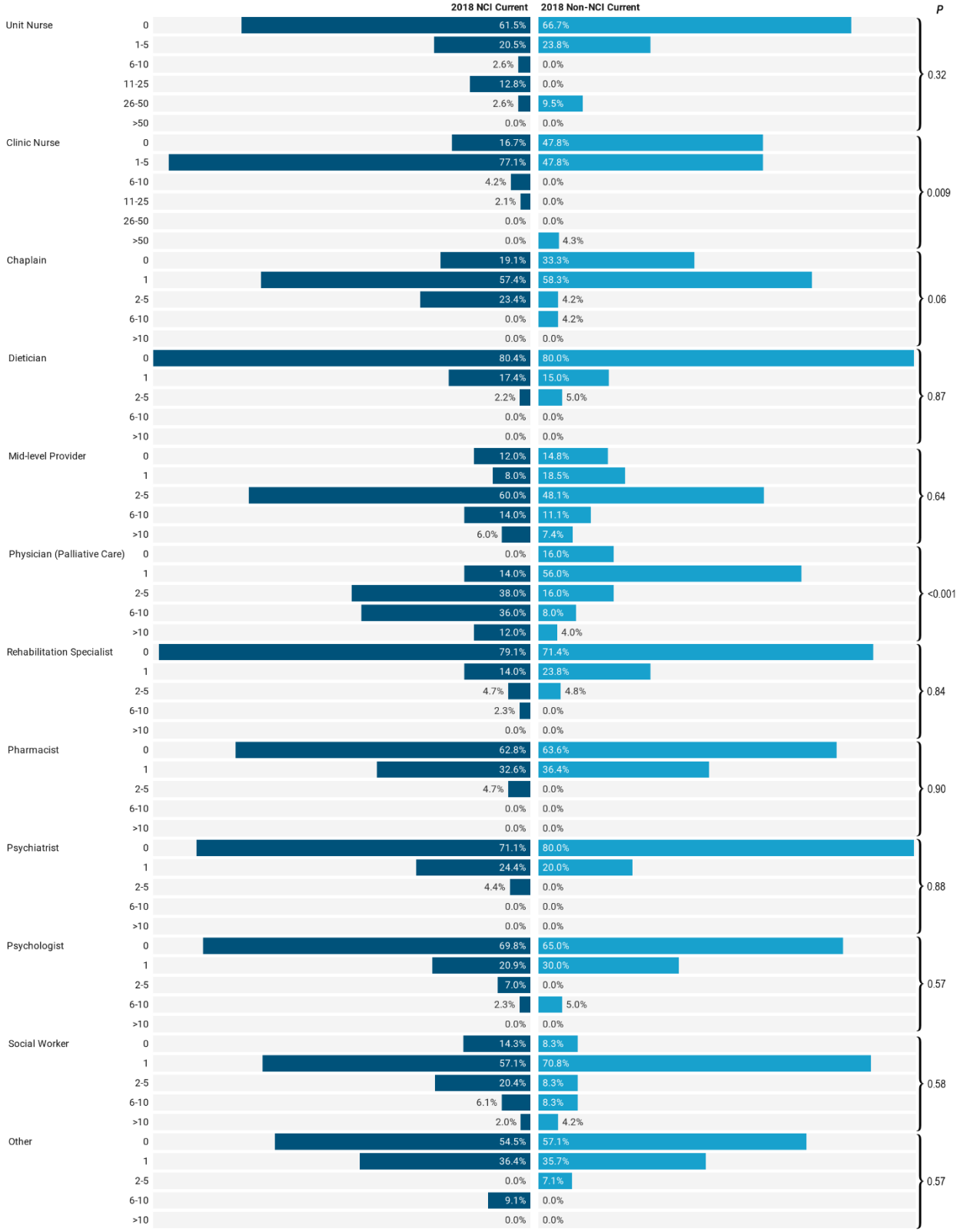
This study presented with several limitations. First, the reliance on self-reported information could have resulted in an overrepresentation of palliative care program capacities. Second, the random sampling of non-NCI-designated cancer centers may not be representative of all non-NCI-designated cancer centers not included in the Commission on Cancer database. Third, the program leader survey questions were intended for cancer centers providing only specialist palliative care services. Fourth, the sample size was small. Only the primary outcome of interdisciplinary team presence was evaluated with a *p* value of 0.05, while other outcomes were considered hypotheses-generating. Lastly, we only examined structure and did not assess the processes and outcomes of interdisciplinary teams.

## CONCLUSION

In this study, interdisciplinary teams were more commonly reported in NCI-designated than non-NCI-designated cancer centers, while the latter were more likely to report nurse-led teams. Psychosocial disciplines, primarily social workers and chaplains were also commonly reported as members of the interdisciplinary teams, although other disciplines were less likely to be present. While some progress has been made in the previous decade, further development of teams in

palliative care programs is to provide comprehensive care to advanced cancer patients and their families, particularly at non-NCI designated cancer centers.

**Figure 1.1:** Palliative Care Team Compositions: NCI vs Non-NCI, 2018




*NCI, National Cancer Institute; PL, Program Leaders; Fisher's exact test was used to examine the change in each variable between the NCI current cohort and non-NCI current cohort*

Chart: Joseph Chen • Source: David Hui, MD

**Table 1.1:** 2018 NCI Current PL vs. 2018 Non-NCI Current PL

| Characteristic | 2018 NCI PL (n=52) No. (%) | 2018 NON-NCI PL (n=27) No. (%) | *P*[c] |
|---|---|---|---|
| Interdisciplinary Team (Physician, Nurse[a], and Psychosocial member)[b] | 46 (92.0%) | 18 (66.7%) | 0.009 |
| Interdisciplinary Team (Physician and Nurse[a])[b] | 49 (98.0%) | 20 (74.1%) | 0.002 |
| Nurse[a] (Unit, Clinic, or Mid-Level Provider)[b] | 49 (98.0%) | 26 (96.3%) | >0.99 |
| Psychosocial Member (Chaplain, Psychologist, Psychiatrist, or Social Worker)[b] | 46 (93.9%) | 23 (95.8%) | >0.99 |
| Physician without nurse[a] present[b] | 1 (2.0%) | 1 (3.7%) | >0.99 |
| Nurse[a] without physician present[b] | 0 (0.0%) | 4 (14.8%) | 0.01 |
| Nurse (Unit or Clinic) | 40 (83.3%) | 18 (66.7%) | 0.10 |
| Unit Nurse | 15 (38.5%) | 7 (33.3%) | 0.69 |
| Clinic Nurse | 40 (83.3%) | 12 (52.2%) | 0.006 |
| Chaplain | 38 (80.9%) | 16 (66.7%) | 0.19 |
| Dietician[b] | 9 (19.6%) | 4 (20.0%) | >0.99 |
| Mid-level Provider[b] | 44 (88.0%) | 23 (85.2%) | 0.73 |
| Physician (Palliative Care)[b] | 50 (100.0%) | 21 (84.0%) | 0.01 |
| Rehabilitation Specialist[b] | 9 (20.9%) | 6 (28.6%) | 0.54 |
| Pharmacist | 16 (37.2%) | 8 (36.4%) | 0.95 |
| Psychiatrist | 13 (28.9%) | 4 (20.0%) | 0.45 |
| Psychologist | 13 (30.2%) | 7 (35.0%) | 0.71 |
| Social Worker[b] | 42 (85.7%) | 22 (91.7%) | 0.71 |
| Other | 10 (45.5%) | 6 (42.9%) | 0.88 |
| Physician certification requirement for American Board of Hospice and Palliative Medicine or American Board of Medical Specialists[b] | 48 (94.1%) | 16 (59.3%) | <0.001 |
| Nurse certification requirement for National Board of Hospice and Palliative Nurses | 22 (44.0%) | 8 (29.6%) | 0.22 |
| Total number of disciplines (Including Other) Median (IQR) | 6 (5, 7) | 5 (3, 7) | 0.08 |
| Total number of disciplines (Excluding other) Median (IQR) | 5.5 (5.0, 7.0) | 5 (3, 7) | 0.05 |
| Full-Time Equivalent Physician positions in Palliative Care Median (IQR) | 4.0 (2.8,7.4) | 1 (1, 3) | <0.001 |
| Number of Physicians with at least 20% protected academic time Median (IQR) | 2 (0, 5) | 0 (0,1) | 0.007 |

Abbreviations: SD, standard deviation; IQR, Interquartile range; NCI, National Cancer Institute; PL, Program leaders

[a]Nurse defined as the presence of a Unit RN, Clinic RN, Mid-level Provider

[b]Fisher's Exact test was used to calculate the p-value for variables with small numbers

[c]Chi-square was used to calculate p-values unless otherwise specified

**Table 1.2:** 2009 NCI PL vs. 2018 NCI Current PL

| Characteristic | 2009 NCI (n=61), No. (%) | 2018 NCI Current (n=52), No. (%) | Odds Ratio (95% CI)[a] | *P*[a] |
|---|---|---|---|---|
| Interdisciplinary Team (Physician, Nurse, and Psychosocial member) | 37 (64.9%) | 46 (92.0%) | 6.09 (2.25, 16.51) | <0.001 |
| Interdisciplinary Team (Physician and Nurse) | 46 (80.7%) | 49 (98.0%) | 11.66 (1.49, 91.55) | 0.02 |
| Nurse (Unit, Clinic, or Mid-Level Provider) | 53 (94.6%) | 49 (98.0%) | 2.74 (0.28, 27.38) | 0.39 |
| Psychosocial Member (Chaplain, Psychologist, Psychiatrist, or Social Worker) | 45 (81.8%) | 46 (93.9%) | 2.60 (1.01, 6.68) | 0.048 |
| Physician without nurse present | 2 (3.5%) | 1 (2.0%) | 0.56 (0.05, 6.40) | 0.64 |
| Nurse without physician present[b] | 4 (7.0%) | 0 (0.0%) | - | - |
| Nurse (Unit or Clinic) | 30 (62.5%) | 40 (83.3%) | 3.06 (1.22, 7.67) | 0.02 |
| Unit Nurse | 16 (39.0%) | 15 (38.5%) | 0.82 (0.36, 1.91) | 0.65 |
| Clinic Nurse | 21 (48.8%) | 40 (83.3%) | 5.33 (2.18, 12.99) | <0.001 |
| Chaplain | 27 (55.1%) | 38 (80.9%) | 3.52 (1.45, 8.54) | 0.01 |
| Dietician | 9 (20.9%) | 9 (19.6%) | 1.00 (0.36, 2.79) | >0.99 |
| Mid-level Provider | 45 (88.2%) | 44 (88.0%) | 1.23 (0.43, 3.51) | 0.70 |
| Physician (Palliative Care)[b] | 49 (90.7%) | 50 (100.0%) | - | - |
| Rehabilitation Specialist | 6 (14.0%) | 9 (20.9%) | 2.83 (0.79, 10.15) | 0.11 |
| Pharmacist | 19 (41.3%) | 16 (37.2%) | 0.84 (0.36, 1.99) | 0.70 |
| Psychiatrist | 8 (19.0%) | 13 (28.9%) | 1.50 (0.46, 4.82) | 0.50 |
| Psychologist | 12 (27.3%) | 13 (30.2%) | 1.25 (0.47, 3.29) | 0.65 |
| Social Worker | 38 (74.5%) | 42 (85.7%) | 1.74 (0.72, 4.22) | 0.22 |
| Other | 9 (37.5%) | 10 (45.5%) | 1.38 (0.43, 4.49) | 0.59 |
| Physician certification requirement for American Board of Hospice and Palliative Medicine or American Board of Medical Specialists | 34 (58.6%) | 48 (94.1%) | 11.30 (3.15, 40.50) | <0.001 |
| Nurse certification requirement for National Board of Hospice and Palliative Nurses | 19 (33.3%) | 22 (44.0%) | 1.55 (0.69, 3.47) | 0.29 |
| Total Number of Disciplines (Including Other) Median (IQR)[c] | 4.0 (3.0, 6.0) | 6.0 (5.0, 7.0) | 1.61 (0.94, 2.29) | <0.0001 |
| Total Number of Disciplines (Excluding Other) Median (IQR)[c] | 4 (3, 6) | 5.5 (5.0, 7.0) | 0.32 (0.93, 2.20) | <0.0001 |
| Full-Time Equivalent Physician Positions in Palliative Care[b,d] Median (IQR) | 1.0 (1.0, 2.0) | 4.0 (2.8, 7.4) | - | - |
| Number of physicians with at least 20% protected academic time[d] Median (IQR) | 0.0 (0.0, 2.0) | 2.0 (0.0, 5.0) | 2.94 (1.37, 6.31) | 0.006 |

Abbreviations: CI, confidence interval; NCI, National Cancer Institute; PL, program leader

[a]Logistic regression via a generalized estimating equation was used to examine the change in each variable between 2009 NCI cohort and the 2018 NCI Current cohort unless otherwise specified

[b]Odds ratio and p-values could not be generated because of extreme values

[c]A generalized estimating equation was used to examine the change in each dichotomous variable. The median and IQR is reported instead of the proportions.

[d]A generalized estimating equation was used to examine the change in each continuous variable. The median and IQR is reported instead of the proportions.

**Table 1.3:** 2009 Non-NCI PL vs. 2018 Non-NCI Current PL

| Characteristic | 2009 Non-NCI (n=35) No. (%) | 2018 Non-NCI Current (n=27) No. (%) | Odds Ratio[a] (95% CI) | *P*[a] |
|---|---|---|---|---|
| Interdisciplinary Team (Physician, Nurse, and Psychosocial member) | 12 (40.0%) | 18 (66.7%) | 3.0 (1,9) | 0.047 |
| Interdisciplinary Team (Physician and Nurse) | 22 (75.9%) | 20 (74.1%) | 0.9 (0,3) | 0.88 |
| Nurse (Unit, Clinic, or Mid-Level Provider) | 25 (86.2%) | 26 (96.3%) | 4.2 (0,40) | 0.22 |
| Psychosocial Member (Chaplain, Psychologist, Psychiatrist, or Social Worker) | 16 (64.0%) | 23 (95.8%) | 12.9 (1,112) | 0.02 |
| Physician (Palliative Care) without nurse present | 2 (6.9%) | 1 (3.7%) | 0.5 (0,6) | 0.60 |
| Nurse without physician present | 0 (0.0%) | 4 (14.8%) | - | >0.99 |
| Nurse (Unit or Clinic) | 14 (60.9%) | 18 (66.7%) | 1.3 (0,4) | 0.67 |
| Unit Nurse | 7 (36.8%) | 7 (33.3%) | 0.9 (0,3) | 0.82 |
| Clinic Nurse | 10 (50.0%) | 12 (52.2%) | 1.1 (0,4) | 0.89 |
| Chaplain | 16 (64.0%) | 16 (66.7%) | 1.1 (0,4) | 0.84 |
| Dietician | 5 (26.3%) | 4 (20.0%) | 0.7 (0,3) | 0.64 |
| Mid-level Provider | 20 (80.0%) | 23 (85.2%) | 1.4 (0,6) | 0.62 |
| Physician (Palliative Care) | 24 (92.3%) | 21 (84.0%) | 0.4 (0,3) | 0.37 |
| Rehabilitation Specialist | 2 (11.1%) | 6 (28.6%) | 3.2 (1,18) | 0.19 |
| Pharmacist | 7 (31.8%) | 8 (36.4%) | 1.2 (0,4) | 0.75 |
| Psychiatrist | 2 (10.5%) | 4 (20.0%) | 2.1 (0,13) | 0.42 |
| Psychologist | 2 (10.5%) | 7 (35.0%) | 4.6 (1,26) | 0.08 |
| Social Worker | 12 (54.5%) | 22 (91.7%) | 9.2 (2,49) | 0.009 |
| Other | 9 (56.3%) | 6 (42.9%) | 0.6 (0,2) | 0.47 |
| Physician certification requirement for American Board of Hospice and Palliative Medicine or American Board of Medical Specialists | 15 (50.0%) | 16 (59.3%) | 1.5 (1,4) | 0.48 |
| Nurse certification requirement for National Board of Hospice and Palliative Nurses | 8 (25.0%) | 8 (29.6%) | 1.3 (0,4) | 0.69 |
| Total Number of Disciplines (Including Other)<br>Median (IQR)[b] | 3.0 (2,6) | 5.0 (3,7) | 1.3 (0.04, 2.6) | 0.04 |
| Total Number of Disciplines (Excluding Other)<br>Median (IQR)[b] | 3.0 (2,5) | 5.0 (3,7) | 1.4 (0.16, 2.57) | 0.03 |
| Full-Time Equivalent Physician Positions in Palliative Care<br>Median (IQR)[c] | 1.0 (0.0, 2.0) | 1.0 (1.0, 3.0) | 5.7 (1.1, 28.8) | 0.04 |
| Number of physicians with at least 20% protected academic time<br>Median (IQR)[c] | 0.0 (0.0, 0.0) | 0.0 (0, 1) | 2.1 (0.6, 6.9) | 0.22 |

Abbreviations: CI, confidence interval; IQR, interquartile range; NCI, National Cancer Institute

[a]Logistic regression was used to examine the change in each dichotomous variable between the 2009 Non-NCI and 2018 Non-NCI Current cohorts unless otherwise specified.

[b]A generalized estimating equation was used to examine the change in each continuous variable between the 2009 non-NCI cohort and the 2018 non-NCI current cohort. The median and IQR is reported instead of the proportions. The parameter estimate and 95% CI is reported instead of the odds ratio.

[c]Logistic regression was used to examine the change in each dichotomous variable. The median and IQR is reported instead of the proportions.

**Table 1.4:** 2009 NCI PL vs. 2018 NCI Previous PL

| Characteristic | 2009 NCI PL (n=61) No. (%) | 2018 NCI PREVIOUS PL (n=54) No. (%) | Odds Ratio (95% CI)[a] | *P*[a] |
|---|---|---|---|---|
| Interdisciplinary Team (Physician, Nurse, and Psychosocial member) | 37 (64.9%) | 45 (86.5%) | 3.74 (1.62, 8.64) | 0.002 |
| Interdisciplinary Team (Physician and Nurse) | 46 (80.7%) | 49 (94.2%) | 3.91 (1.03, 14.87) | 0.045 |
| Nurse (Unit, Clinic, or Mid-Level Provider) | 53 (94.6%) | 51 (98.1%) | 2.79 (0.29, 27.29) | 0.38 |
| Psychosocial Member (Chaplain, Psychologist, Psychiatrist, or Social Worker) | 45 (81.8%) | 45 (91.8%) | 2.51 (1.04, 6.04) | 0.04 |
| Physician without nurse present | 2 (3.5%) | 1 (1.9%) | 0.55 (0.05, 6.29) | 0.63 |
| Nurse without physician present | 4 (7.0%) | 1 (1.9%) | 0.26 (0.03, 2.39) | 0.23 |
| Nurse (Unit or Clinic) | 30 (62.5%) | 41 (83.7%) | 3.15 (1.27, 7.78) | 0.01 |
| Unit Nurse | 16 (39.0%) | 13 (33.3%) | 0.68 (0.30, 1.54) | 0.36 |
| Clinic Nurse | 21 (48.8%) | 40 (83.3%) | 5.33 (2.22, 12.80) | <0.001 |
| Chaplain | 27 (55.1%) | 37 (80.4%) | 3.36 (1.45, 7.82) | 0.005 |
| Dietician | 9 (20.9%) | 11 (24.4%) | 1.24 (0.45, 3.45) | 0.68 |
| Mid-level Provider | 45 (88.2%) | 46 (88.5%) | 1.28 (0.44, 3.75) | 0.65 |
| Physician (Palliative Care) | 49 (90.7%) | 50 (98.0%) | 5.10 (0.57, 45.28) | 0.14 |
| Rehabilitation Specialist | 6 (14.0%) | 10 (23.8%) | 2.10 (0.63, 6.99) | 0.23 |
| Pharmacist | 19 (41.3%) | 13 (31.0%) | 0.64 (0.27, 1.55) | 0.33 |
| Psychiatrist | 8 (19.0%) | 13 (29.5%) | 1.54 (0.58, 4.09) | 0.39 |
| Psychologist | 12 (27.3%) | 13 (30.2%) | 1.22 (0.52, 2.84) | 0.65 |
| Social Worker | 38 (74.5%) | 41 (83.7%) | 1.64 (0.71, 3.78) | 0.25 |
| Other | 9 (37.5%) | 9 (42.9%) | 1.25 (0.38, 4.11) | 0.72 |
| Physician certification requirement for American Board of Hospice and Palliative Medicine or American Board of Medical Specialists | 34 (58.6%) | 45 (86.5%) | 4.41 (1.60, 12.10) | 0.004 |
| Nurse certification requirement for National Board of Hospice and Palliative Nurses | 19 (33.3%) | 21 (40.4%) | 1.27 (0.56, 2.87) | 0.57 |
| Total Number of Disciplines (Including Other)[b] | 4.0 (3.0, 6.0) | 6.0 (4.0, 7.0) | 1.32 (0.64, 2.01) | .0002 |
| Total Number of Disciplines (Excluding Other)[b] | 4.0 (3.0, 6.0) | 5.0 (4.0, 7.0) | 1.30 (0.65, 1.95) | <0.0001 |
| Full-Time Equivalent Physician Positions in Palliative Care Median (IQR)[c] | 1.0 (1.0, 2.0) | 3.5 (1.9, 6.0) | 2.46 (0.47, 12.91) | 0.29 |
| Number of physicians with at least 20% protected academic time Median (IQR)[c] | 0.0 (0.0, 2.0) | 1.0 (0.0, 5.0) | 1.84 (0.93, 3.63) | 0.08 |

Abbreviations: CI, confidence interval; NCI, National Cancer Institute; PL, program leader

[a]Logistic regression via a generalized estimating equation was used to examine the change in each dichotomous variable between 2009 NCI cohort and the 2018 NCI Previous Cohort unless otherwise specified

[b]Logistic regression via a generalized estimating equation was used to examine the change in each continuous variable. The parameter estimate and 95% CI is reported instead of the odds ratio.

[c]Logistic regression via a generalized estimating equation was used to examine the change in each dichotomous variable. The median and IQR is reported instead of the proportions.

**Table 1.5:** 2009 Non-NCI PL vs. 2018 Non-NCI Previous PL

| Characteristic | 2009 Non-NCI PL (n=35) No. (%) | 2018 Non-NCI Previous PL (n=35) No. (%) | Odds Ratio (95% CI)[a] | *P*[a] |
|---|---|---|---|---|
| Interdisciplinary Team (Physician, Nurse, and Psychosocial member) | 12 (40.0%) | 22 (64.7%) | 3.13 (1.27, 7.73) | 0.01 |
| Interdisciplinary Team (Physician and Nurse) | 22 (75.9%) | 27 (79.4%) | 1.41 (0.59, 3.38) | 0.45 |
| Nurse (Unit, Clinic, or Mid-Level Provider) | 25 (86.2%) | 31 (93.9%) | 1.00 (1.00, 1.00) | 0.30 |
| Psychosocial Member (Chaplain, Psychologist, Psychiatrist, or Social Worker) | 16 (64.0%) | 28 (96.6%) | 15.66 (1.81, 135.73) | 0.01 |
| Physician without nurse present | 2 (6.9%) | 1 (2.9%) | 0.42 (0.04, 4.31) | 0.46 |
| Nurse without physician present[b] | 0 (0.0%) | 1 (2.9%) | - | - |
| Nurse (Unit or Clinic) | 14 (60.9%) | 21 (80.8%) | 2.69 (0.75, 9.71) | 0.13 |
| Unit Nurse | 7 (36.8%) | 14 (58.3%) | 2.81 (0.92, 8.54) | 0.07 |
| Clinic Nurse | 10 (50.0%) | 14 (63.6%) | 1.73 (0.50, 6.04) | 0.39 |
| Chaplain | 16 (64.0%) | 19 (79.2%) | 1.08 (0.28, 4.22) | 0.91 |
| Dietician | 5 (26.3%) | 4 (19.0%) | 0.71 (0.26, 1.97) | 0.51 |
| Mid-level Provider | 20 (80.0%) | 25 (86.2%) | 1.89 (0.61, 5.89) | 0.27 |
| Physician (Palliative Care) | 24 (92.3%) | 29 (93.5%) | 1.00 (1.00, 1.00) | 0.90 |
| Rehabilitation Specialist | 2 (11.1%) | 2 (10.5%) | 0.89 (0.11, 7.45) | 0.91 |
| Pharmacist | 7 (31.8%) | 4 (20.0%) | 0.97 (0.92, 1.02) | 0.28 |
| Psychiatrist | 2 (10.5%) | 1 (5.0%) | 0.46 (0.05, 4.48) | 0.50 |
| Psychologist | 2 (10.5%) | 3 (13.6%) | 1.30 (0.25, 6.72) | 0.75 |
| Social Worker | 12 (54.5%) | 22 (78.6%) | 3.03 (0.88, 10.45) | 0.08 |
| Other | 9 (56.3%) | 2 (25.0%) | 0.26 (0.04, 1.65) | 0.15 |
| Physician certification requirement for American Board of Hospice and Palliative Medicine or American Board of Medical Specialists | 15 (50.0%) | 23 (74.2%) | 2.85 (1.00, 8.09) | 0.049 |
| Nurse certification requirement for National Board of Hospice and Palliative Nurses | 8 (25.0%) | 11 (33.3%) | 1.00 (0.27, 3.71) | >0.99 |
| Total Number of Disciplines (Including Other)[c] Median (IQR) | 3 (2, 6) | 4 (3, 5) | 0.49 (-0.43, 1.39) | 0.30 |
| Total Number of Disciplines (Excluding Other)[c] Median (IQR) | 3 (2, 5) | 4 (3, 5) | 0.75 (-0.12, 1.62) | .10 |
| Full-Time Equivalent Physician Positions in Palliative Care[d] Median (IQR) | 1.0 (0.0, 2.0) | 2.0 (1.0, 3.0) | 5.32 (1.33, 21.24) | 0.02 |
| Number of physicians with at least 20% protected academic time[d] Median (IQR) | 0.0 (0.0, 0.0) | 0.0 (0.0, 1.0) | 1.36 (0.47, 3.92) | 0.57 |

Abbreviations: CI, confidence interval; NCI, National Cancer Institute; PL, program leader

[a]Logistic regression via a generalized estimating equation was used to examine the change in each variable between 2009 Non-NCI and 2018 Non-NCI Previous cohort. The odds ratio and 95% CI is reported unless otherwise specified.

[b]Odds ratio and p-values could not be generated because of small sample size or large variation in cohorts

[c]The generalized estimating equation parameter estimate and 95% CI is reported instead of the odds ratio for the continuous variable.

[d]Logistic regression via a generalized estimating equation was used to examine the change in each dichotomous variable. The median and IQR is reported instead of the proportions.

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JOURNAL ARTICLE

**Cancer Center Executives' Attitudes towards Palliative Care Integration**

Journal of Pain and Symptom Management

**ABSTRACT**

**Context:** Cancer center executives have a key role defining the future of palliative care.

**Objectives:** To compare cancer center executives' attitudes towards palliative care between National Cancer Institute-designated cancer centers (NCI-CCs) and non-NCI-designated cancer centers (non-NCI-CCs) in 2018 and to examine the changes in attitudes and beliefs between 2009 and 2018.

**Methods:** Cancer center chief executives at all NCI-CCs and a random sample of non-NCI-CCs were surveyed from April to August 2018. Twelve questions examined the executives' attitudes towards palliative care integration, perceived barriers, and self-assessments. The primary outcome was agreement on the statement "a stronger integration of palliative care services into oncology practice will benefit patients at my institution."

**Results:** 52/77 (68%) NCI-CCs and 88/126 (70%) non-NCI-CCs responded to the survey. A vast majority of executives at NCI-CCs and non-NCI-CCs endorsed palliative care integration (89.7% vs 90.0%; $P>0.999$). NCI-CCs were more likely to endorse increasing funding for palliative care (52.5% vs 23.1%; $P=0.01$) and hiring physician specialists (70.0% vs 37.5%; $P=0.004$) than non-NCI-CCs. The top 3 perceived barriers among NCI-CCs and non-NCI-CCs were limited institutional budgets (57.9% vs 59.0%; $P=0.92$), poor reimbursements (55.3% vs 43.6%; $P=0.31$), and lack of adequately trained palliative care physicians and nurses (52.6% vs 43.6%; $P=0.43$). Both NCI-CCs and non-NCI-CCs favorably rated their palliative care services (89.7% vs 71.8%; $P=0.04$) with no major changes since 2009.

**Conclusion:** Cancer center executives endorse integration of palliative care, with greater willingness to invest in palliative care among NCI-CCs. Resource limitation continues to be a major barrier.

## INTRODUCTION

Concurrent palliative care and standard oncologic care improve symptom burden, quality of life, psychological outcomes, patient satisfaction, caregiver distress,[1] and lowers costs of care associated with preventable inpatient admissions.[2] The early integration of palliative care into the conventional cancer treatment timeline is recommended by the American Society of Clinical Oncology,[3] National Comprehensive Cancer Network,[4] Commission on Cancer (CoC),[5] European Society of Medical Oncology (ESMO),[6] and the World Health Organization.[7]

Cancer center chief executives have an essential role defining the direction of cancer care. We conducted a national survey of cancer center executives in 2009 to understand their attitudes and beliefs toward palliative care.[8] We found that cancer center executives were generally supportive of palliative care integration but expressed some reservations about resource allocation.[8] Davis and colleagues later adapted the survey to evaluate NCI-designated, ESMO-designated, and urban cancer centers in Europe.[9] This survey reported similar findings and consistently identified financial constraints and insufficiently skilled staff as perceived barriers.

Since the 2009 survey, several landmark studies have reported patient and caregiver benefits associated with palliative care, garnering momentous support for integration.[10-12] We recently reported that palliative care services at cancer centers have grown significantly over the past decade, particularly in outpatient clinics. However, there remain major deficiencies in

clinical infrastructure, education and research at both NCI and non-NCI designated cancer centers.[13-15] It is unclear how cancer center executives view palliative care integration at their institution at this time when there are many novel cancer therapeutic options and competing developmental priorities. A better understanding of the attitudes and beliefs among cancer center executives towards palliative care will help inform the future advancements of this field. The objective of this study to compare executives' attitudes towards palliative care between NCI (National Cancer Institute)-designated and non-NCI-designated cancer centers in 2018 and to compare changes in executives' attitudes towards palliative care between 2009 and 2018.

## MATERIALS AND METHODS

### Study Design

This was a prospective cross-sectional study surveying chief executives from NCI-designated and non-NCI-designated cancer centers in the United States in 2018. This study followed the methodology of a national survey previously conducted in 2009.[8] To facilitate direct comparison, we kept all questions the same. Questions were developed according to the Donabedian framework of structure, process, and outcome.[16] Cancer center executives were considered knowledgeable about institutional-level agendas regarding palliative care programs. We recently reported on the availability of palliative care services based on this executive survey.[13] This secondary analysis focused on 12 questions examining palliative care attitudes, barriers to access, and self-assessments. Approval and exemption status were granted by Institutional Review Boards at The University of Texas MD Anderson Cancer Center and The University of Texas Health Science Center.

**Survey Population**

All cancer centers were obtained from an online database and accredited by the CoC, a consortium of professional organizations setting compliance standards for patient care, quality initiatives, research, and education.[16] We further classified centers as NCI-designated or non-NCI-designated. Fewer than 5% of CoC-accredited centers received NCI designation status, a recognition for leadership in clinical trial recruitment, provision of cutting-edge cancer treatments, and administrant of training opportunities.[17] Even though the collective majority of cancer programs providing care to patients are without NCI designation, those with NCI designation typically encounter higher patient volumes by site.

At the time of our 2009 survey distribution, there were 1482 CoC-accredited programs comprising of 71 NCI-designated and 1411 non-NCI-designated cancer centers in the database. In 2018, there were 1314 CoC-accredited programs consisting of 62 NCI-designated centers and 1252 non-NCI-designated cancer centers. Centers were categorized by survey year and NCI designation status, totaling 6 cohorts: 2009 NCI, 2009 non-NCI, 2018 NCI current, 2018 NCI previous, 2018 non-NCI current, and 2018 non-NCI previous. “Current” centers were new samples in 2018, while “previous” centers were 2009 cohorts resurveyed in 2018. All NCI-designated cancer centers were surveyed. Since the number of non-NCI-designated cancers outnumbered NCI-designated cancer centers by over 20-fold, we obtained a comparably sized random selection of the former using the function “=RAND()” in Microsoft Excel for Windows 10 (Office 2016, Microsoft Corp., Redmond, W.A., USA). This was applicable to the 2018 non-NCI current cohort. Further detailing of sampling methodology has been reported elsewhere.[13]

**Survey Questions**

Survey questions addressed palliative care attitudes, perceived barriers, and self-assessments. There were 7 questions on attitudes, 1 question with 9 subcomponents on barriers, and 4 questions on self-assessments. The survey questions are shown in Table 1. Attitudes questions addressed palliative care integration; research funding; increasing palliative care staff: physicians, mid-level providers (advanced practice nurse practitioners, physician assistants), and staff nurses; number of palliative care acute beds; and palliative care funding over the next 5 years. The responses were assessed using a 0-10 numeric rating scale, where 0=strongly disagree and 10=strongly agree.

We inquired about the following barriers to integration: limited palliative care needs; limited institutional budget; poor reimbursement; lack of adequately trained palliative care physicians and nurses; lack of evidence to suggest palliative care improves patient outcomes; concern that palliative care may increase hospital mortality; negative impact on institution's national rating; available but not utilized frequently; and other. Respondents were asked to check all that applied.

We also asked executives to self-rate the quality of their pain management and palliative care services 5 years ago and now. Their responses were assessed using a 0-10 numeric rating scale, where 0=poor and 10=excellent.

**Data Collection**

Data collection occurred between April and August 2018. Executive appointments were confirmed by phone after internet search. Paper surveys were mailed to executives along with instructions and a $10 gift card, despite intent to participate. A secure electronic survey option

(https://www.qualtrics.com) was provided as an alternative. Letter reminders were mailed at 2 and 4 weeks, while email and phone reminders were made at 8 weeks.

**Statistical Analysis**

Prior to data collection, sample size justifications were based on a standard error of ≤0.079 calculated from a response rate of 65% for 61 available outpatient palliative care clinics.[13] The primary outcome was a statistically significant difference between NCI-designated and non-NCI-designated cancer centers on consensus for the statement "a stronger integration of palliative care services into oncology practice will benefit patients at my institution." Secondary outcomes included questions on attitudes, barriers, and self-assessments.

Methodology for response rate calculations were derived from 2016 definitions by the American Association for Public Health Research.[18] For analysis purposes, we coded responses to questions on attitudes on integration as follows: 7-10=agree or strongly agree, 4-6=neutral, 0-3= strongly disagree or disagree. Our analyses further required coding to dichotomous outcomes as follows: 7-10: agree, 0-6: disagree. Barriers questions were considered yes or no and were coded as binary for analyses. Coding was consistent with that of our previous survey to facilitate comparisons.

Data analyses were performed with SAS Version 9.4 for Windows 10 and IBM SPSS Statistics for Windows, version 24 (IBM Corp., Armonk, N.Y., USA). Descriptive statistics were generated for all variables. Comparisons were made between cancer centers organized into cohorts by year and NCI-designation. Chi-square and Fisher's Exact tests were used to obtain *p* values for the primary comparison between the 2018 NCI current and 2018 non-NCI current cohorts. Secondary and exploratory comparisons to obtain odds ratios used logistic regression

via generalized estimating equations (GEE) to compare cohorts with overlapping cancer centers (partially matched), and traditional logistic regression to compare non-overlapping (unmatched) cohorts. Secondary comparisons involved cancer centers surveyed in 2009 and a new sample in 2018: 2009 NCI and 2018 NCI current (partially matched); and 2009 non-NCI and 2018 non-NCI current (unmatched). Exploratory comparisons were made between 2009 cancer centers and the same group resurveyed in 2018: 2009 NCI and 2018 NCI previous (partially matched); and 2009 non-NCI and 2018 non-NCI previous (partially matched). Statistical significance for the primary outcome was based on a *p* value cutoff of 0.05 or less. Analyses of other variables were considered exploratory and hypotheses generating. Visualizations were created using DataWrapper (Berlin Prenzlauer Berg, Germany).

## RESULTS

### Survey Response Rate

The executives survey yielded an overall response rate of 140/203 (69%), completed by 52/77 (68%) NCI-designated centers and 88/126 (70%) non-NCI-designated centers. No statistically significant difference was found between NCI-designated and non-NCI-designated cancer centers (*P*=0.87), nor was geographical variation found among randomly sampled non-NCI-designated cancer centers in 2018 (*P*=0.35).

### Attitudes towards Integration: NCI-designated and Non-NCI-designated Cancer Centers in 2018

A vast majority of NCI-designated and non-NCI-designated cancer center executives endorsed palliative care integration (89.7% vs 90.0%; *P*>0.999), more research funding (87.2% vs 80.0%;

*P*=0.39), hiring additional mid-level providers (65.0% vs 52.5%; *P*=0.26) and staff nurses (47.5% vs 41.0%; *P*=0.56) at their cancer centers, with no statistically significant differences observed between cohorts. NCI-designated cancer center executives were more likely to endorse hiring more palliative care physicians (70.0% vs 37.5%; *P*=0.004) and to increase program funding (52.5% vs 23.1%; *P*=0.01) over the next 5 years.

**Attitudes towards Integration: 2009 vs. 2018**

Compared to 2009, we found no significant changes in the attitudes and beliefs toward integration among cancer center executives at NCI-designated cancer centers (Table 2.2, Table 2.5) and non-NCI-designated cancer centers (Table 2.3, Table 2.6). There was only 1 exception. A greater proportion of non-NCI-designated cancer center executives resurveyed in 2018 expressed more support to hire mid-level providers (32.6% vs 60.4%; *P*=0.003).

**Perceived Barriers to Access: NCI-designated and Non-NCI-designated Cancer Centers in 2018**

Among NCI-designated and non-NCI-designated cancer centers, the most commonly perceived barriers were limited budgets (57.9% vs 59.0%; *P*=0.92), poor reimbursements (55.3% vs 43.6%; *P*=0.31), and lack of adequately trained palliative care physicians and nurses (52.6% vs 43.6%; *P*=0.43), with no statistically significant differences between cohorts.

Very few cancer center executives reported that the lack of evidence for palliative care (2.6% vs 0.0%; *P*=0.49), negative impact to institution's national rating (2.6% vs 5.1%; *P*>0.99), and limited palliative care needs in the institution (2.6% vs 7.7%, *P*>0.99) represented as barriers. There were no statistically significant differences between the two cohorts.

**Perceived Barriers to Access: 2009 vs. 2018**

Comparing the responses between 2009 and 2018, executives at NCI-designated cancer centers were less likely to report limited institution budgets (70.6% vs 57.9%; *P*=0.03) and poor reimbursements (74.5% vs 55.3%; *P*=0.01) as barriers to developing palliative care, and more likely to report the lack of adequately trained palliative care physicians and nurses (27.5% vs 52.6%; *P*=0.02) as a concern**.**

**Self-Assessments: NCI-designated and Non-NCI-designated Cancer Centers in 2018**

In 2018, NCI-designated and non-NCI-designated cancer centers favorably rated their current pain management services (71.8% vs 82.5%; *P*=0.26) and palliative care services (89.7% vs 71.8%; *P*=0.04), reporting substantial improvements from 5 years prior for both. A greater proportion of NCI-designated cancer centers scored their current palliative care services as good or excellent compared to non-NCI-designated cancer centers (89.7% vs 71.8%; *P*=0.04).

**Self-Assessments: 2009 vs. 2018**

Pain management and palliative care services were rated favorably in NCI-designated and non-NCI-designated cancer centers from 2009 to 2018. Considerable increases were observed from 5 years prior to current for all cohorts. 2018 non-NCI-designated cancers resurveyed from 2009 were more likely to rate their current palliative care services more positively (83.0% vs 57.4%; *P*=0.002).

## DISCUSSION

In this national survey, we found that 9 of 10 executives from NCI-designated and non-NCI-designated cancer centers supported the integration of palliative care into oncology practice. NCI-designated cancer centers were more inclined to expand palliative care programs and hire additional staff compared to non-NCI-designated cancer centers. Over the last decade, perceived barriers have largely remained the same and consisted of limited budgets, poor reimbursements, and lack of adequately trained palliative care physicians and nurses. Our findings highlight possibilities for further growth in palliative care and also opportunities to overcome challenging barriers to integration.

We found that there was almost universal endorsement for palliative care integration among cancer center executives at both NCI-designated and non-NCI-designated cancer centers. Cancer center executives have a critical role shaping the level of palliative care development at their institutions through setting institutional priorities, allocating precious resources, and hiring personnel. The relatively high response rate in this national survey suggests that this topic is likely of interest to cancer center executives. In our 2009 survey, NCI executives expressed more willingness to hire palliative care physicians than non-NCI executives (56% vs 25%; $P$=0.005). Indeed, our 2018 data confirmed that more NCI-designated cancer centers had interdisciplinary teams with palliative care physicians while non-NCI-designated cancer centers were more likely to report having nurse-led palliative care teams.[19] Furthermore, NCI-designated cancer centers have been found to have more integrated palliative care services than non-NCI-designated cancer centers.[14] These findings indirectly support that executives' attitudes and beliefs can have meaningful downstream impacts. It is encouraging that in 2018, executives remained highly interested in the integration of palliative care at their institutions, suggesting a potential for

further growth in the coming decade. The lack of further increase between 2009 and 2018 may be related to a ceiling effect.

The 3 most commonly perceived barriers to palliative care access continue to be limited budgets, poor reimbursements, and lack of adequately trained personnel. Although palliative care integration is strongly supported, cancer center executives are required to weigh program development against other institutional priorities. It is encouraging to see that executives at NCI-designated cancer cancers perceived that financial constraints were less of a barrier now compared to 10 years ago, and that lack of staffing was an increasing concern, suggesting a subtle shift in prioritization among these executives.

Even if executives are willing to hire more palliative care staff, workforce shortages remains a concern, particularly given the aging population.[20] In a companion survey to palliative care program leaders, we found that NCI-designated cancer centers significantly increased their number of fellowships and mandatory medical oncology rotations,[15] while non-NCI-designated cancer centers made limited progress. Given the expressed interest among executives, fellowship programs should consider substantially increasing the training for palliative care team members, including physicians, nurses, pharmacists, social workers, psychologists and other allied health professionals.

A majority of executives at NCI-designated and non-NCI-designated cancer centers considered their palliative care services to be “good or excellent” and better compared to those from 5 years ago. NCI-designated cancer centers’ self-assessments were significantly higher than those of non-NCI-designated cancer centers. Although these assessments were based on self-reports and thus could be biased, the pattern was generally consistent with our separate assessment of their palliative care programs based on 13 indicators of integration.[14] These

indicators were developed using a Delphi study, and examined clinical, educational, and research-related aspects of integration.[21] We found that NCI-designated cancer centers had a higher median integration index compared to that of non-NCI-designated cancer centers (PCOI-13 median [interquartile range], 8.8 [7.4-10.7] vs 7.7 [5.2-8.5]; *P*=0.01).[14] This higher level of integration may be in turn related to the stronger support among NCI-designated cancer centers as seen in this survey.

Previous studies have used identical or adapted survey questions, and found considerable support for palliative care integration among NCI-designated and non-NCI-designated cancer centers in the US[8] and ESMO-designated cancer centers[9] in Europe (Table 4). However, executives at NCI-designated cancer centers in our survey appeared to be more open to hiring additional physicians (2018 NCI vs Other; 70% vs 12-39%), mid-level providers (2018 NCI vs Other; 65% vs 19-52.5%), nurses (2018 NCI vs Other; 48% vs 14-41%), and increasing funding for palliative care programs (2018 NCI vs Other; 53% vs 9-28%) compared to data from the two previous surveys.

Recognizing the interest in palliative care among executives and the barriers they perceived may allow us to identify potential solutions. One solution would be increasing national healthcare resources allocated to palliative care. Another would be to offer accreditations through a commissioning body. Although the CoC has recommended palliative care access for patients, there are no specifications whether cancer centers should provide these services, as patients can be referred to other centers. Accreditation standards may help to establish the minimal requirements for palliative care programs.[22] In addition, several organizations such as ESMO have supported a recognition program for cancer centers that have attained a high level of palliative care integration.[21,23] Such distinctions may help patients become more educated in

choosing a suitable treatment center. In the meanwhile, COVID-19 has significantly increased the use of telemedicine for palliative care encounters[24] and can serve as a cost-effective approach to expanding palliative care.

This study has several limitations. First, this cross-sectional survey relied on self-reported assessments that could be subject to bias. Second, the random sampling of non-NCI-designated cancer centers may not be representative of cancer centers excluded from non-CoC-accredited programs, although variation was not found by geographical region for those sampled. Lastly, the sample size was small. Only the primary outcome was analyzed with a *p* value of less than 0.05, while the other outcomes were considered exploratory and hypotheses-generating.

## CONCLUSION

Cancer center executives are influential to setting the pace of growth for palliative care programs. Given the high level of interest among executives, we expect palliative care programs to continue expanding in the upcoming years. In anticipation of these developments, much work remains ahead to build the clinical infrastructure to support patient care needs, to further expand educational programs to train the next generation of palliative care specialists, and to develop more research to support evidence-based practice, while advocating for more resources to support these efforts and more regulatory guidance to standardize the quality of care delivery.

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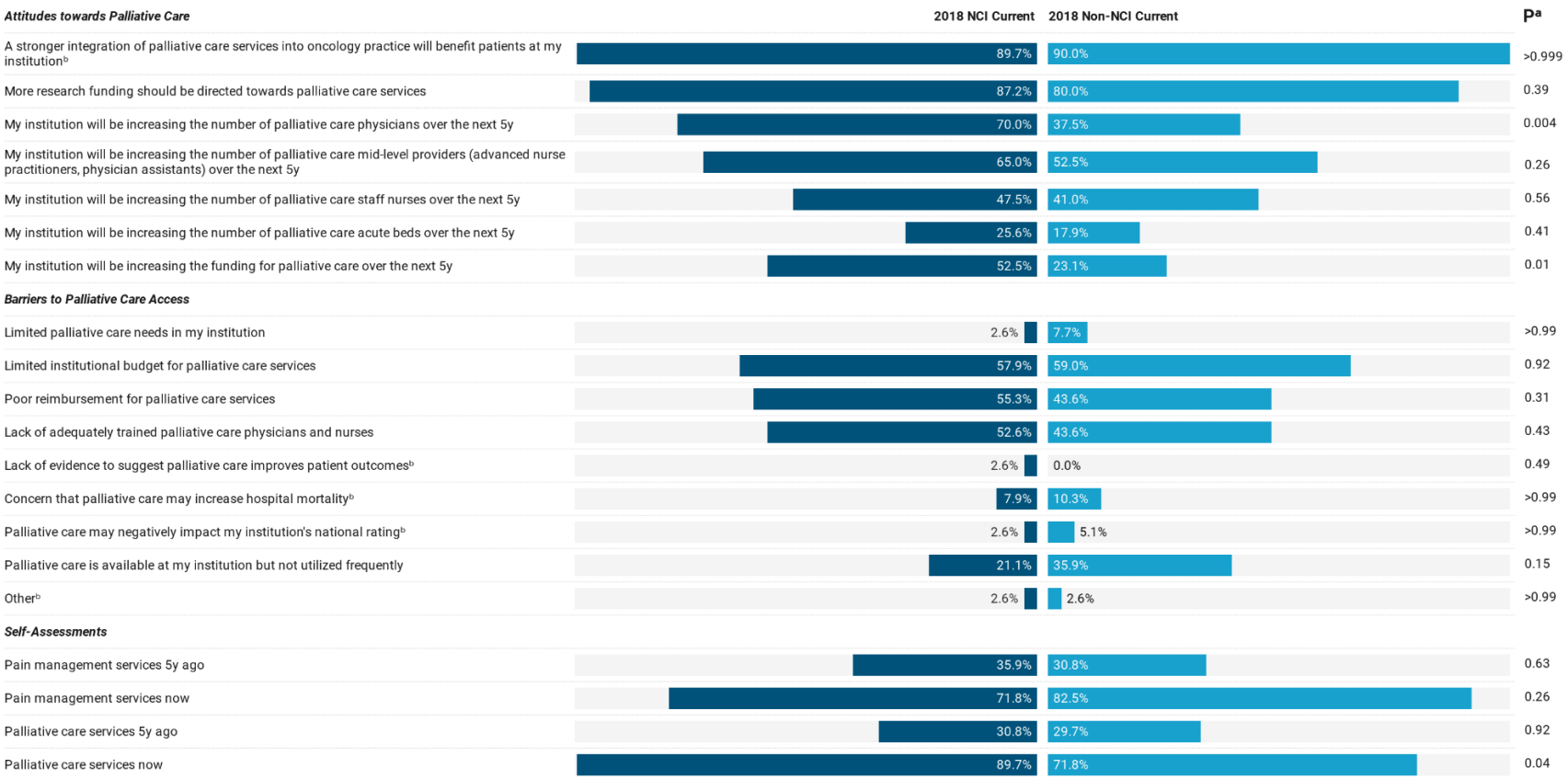
**Figure 2.1:** Palliative Care Attitudes, Barriers, and Self-Assessments




*Abbreviations: NCI, National Cancer Institute; EX, executive. Respondents specified their degree of agreement using a 0-10 numeric rating scale from 'strongly disagree' to 'strongly agree' for attitudes; and 'poor' to 'excellent' for self-assessments. [a]Chi-Square test was used to examine the change in each variable unless otherwise specified. All Attitudes and Beliefs & Self-Assessments were ordinal variables and recoded as dichotomous. All Barriers to Palliative Access variables were dichotomous. [b]Fisher's Exact Test was used for variables with small counts (n<5).*

Chart: Joseph Chen • Source: David Hui, MD • Created with Datawrapper

**Table 2.1:** 2018 NCI Current EX vs. 2018 Non-NCI Current EX

| Characteristic[a] | Category | 2018 NCI Current EX (n=40) No. (%) | 2018 Non-NCI Current EX (n=40) No. (%) | *P* |
|---|---|---|---|---|
| **Attitudes towards Palliative Care Integration** | | | | |
| A stronger integration of palliative care services into oncology practice will benefit patients at my institution[b] | Agree or strongly agree | 35 (89.7%) | 36 (90.0%) | >0.999 |
| | Neutral | 4 (10.3%) | 4 (10.0%) | |
| | Disagree or strongly disagree | 0 (0.0%) | 0 (0.0%) | |
| More research funding should be directed towards palliative care services | Agree or strongly agree | 34 (87.2%) | 32 (80.0%) | 0.39 |
| | Neutral | 5 (12.8%) | 8 (20.0%) | |
| | Disagree or strongly disagree | 0 (0.0%) | 0 (0.0%) | |
| My institution will be increasing the number of palliative care physicians over the next 5y | Agree or strongly agree | 28 (70.0%) | 15 (37.5%) | 0.004 |
| | Neutral | 12 (30.0%) | 22 (55.0%) | |
| | Disagree or strongly disagree | 0 (0.0%) | 3 (7.5%) | |
| My institution will be increasing the number of palliative care mid-level providers (advanced nurse practitioners, physician assistants) over the next 5y | Agree or strongly agree | 26 (65.0%) | 21 (52.5%) | 0.26 |
| | Neutral | 14 (35.0%) | 15 (37.5%) | |
| | Disagree or strongly disagree | 0 (0.0%) | 4 (10.0%) | |
| My institution will be increasing the number of palliative care staff nurses over the next 5y | Agree or strongly agree | 19 (47.5%) | 16 (41.0%) | 0.56 |
| | Neutral | 18 (45.0%) | 19 (48.7%) | |
| | Disagree or strongly disagree | 3 (7.5%) | 4 (10.3%) | |
| My institution will be increasing the number of palliative care acute beds over the next 5y | Agree or strongly agree | 10 (25.6%) | 7 (17.9%) | 0.41 |
| | Neutral | 20 (51.3%) | 23 (59.0%) | |
| | Disagree or strongly disagree | 9 (23.1%) | 9 (23.1%) | |
| My institution will be increasing the funding for palliative care over the next 5y | Agree or strongly agree | 21 (52.5%) | 9 (23.1%) | 0.01 |
| | Neutral | 19 (47.5%) | 27 (69.2%) | |
| | Disagree or strongly disagree | 0 (0.0%) | 3 (7.7%) | |
| **Barriers to Palliative Care Access** | | | | |
| Limited palliative care needs in my institution | Yes | 1 (2.6%) | 3 (7.7%) | >0.99 |
| | No | 37 (97.4%) | 36 (92.3%) | |
| Limited institutional budget for palliative care services | Yes | 22 (57.9%) | 23 (59.0%) | 0.92 |
| | No | 16 (42.1%) | 16 (41.0%) | |
| Poor reimbursement for palliative care services | Yes | 21 (55.3%) | 17 (43.6%) | 0.31 |
| | No | 17 (44.7%) | 22 (56.4%) | |
| Lack of adequately trained palliative care physicians and nurses | Yes | 20 (52.6%) | 17 (43.6%) | 0.43 |
| | No | 18 (47.4%) | 22 (56.4%) | |
| Lack of evidence to suggest palliative care improves patient outcomes[b] | Yes | 1 (2.6%) | 0 (0.0%) | 0.49 |
| | No | 37 (97.4%) | 39 (100.0%) | |
| Concern that palliative care may increase hospital mortality[b] | Yes | 3 (7.9%) | 4 (10.3%) | >0.99 |
| | No | 35 (92.1%) | 35 (89.7%) | |
| Palliative care may negatively impact my institution's national rating[b] | Yes | 1 (2.6%) | 2 (5.1%) | >0.99 |
| | No | 37 (97.4%) | 37 (94.9%) | |
| Palliative care is available at my institution but not utilized frequently | Yes | 8 (21.1%) | 14 (35.9%) | 0.15 |
| | No | 30 (78.9%) | 25 (64.1%) | |
| Other[b] | Yes | 1 (2.6%) | 1 (2.6%) | >0.99 |
| | No | 37 (97.4%) | 38 (97.4%) | |
| **Self-Assessments** | | | | |
| Pain management services 5y ago | Good or excellent | 14 (35.9%) | 12 (30.8%) | 0.63 |
| | Neutral | 23 (59.0%) | 24 (61.5%) | |
| | Poor | 2 (5.1%) | 3 (7.7%) | |
| Pain management services now | Good or excellent | 28 (71.8%) | 33 (82.5%) | 0.26 |
| | Neutral | 11 (28.2%) | 7 (17.5%) | |
| | Poor | 0 (0.0%) | 0 (0.0%) | |
| Palliative care services 5y ago | Good or excellent | 12 (30.8%) | 11 (29.7%) | 0.92 |
| | Neutral | 21 (53.8%) | 12 (32.4%) | |
| | Poor | 6 (15.4%) | 14 (37.8%) | |
| Palliative care services now | Good or excellent | 35 (89.7%) | 28 (71.8%) | 0.04 |
| | Neutral | 4 (10.3%) | 6 (15.4%) | |
| | Poor | 0 (0.0%) | 5 (12.8%) | |

**Note**: Abbreviations: NCI, National Cancer Institute; EX, executive.
[a]All p-values obtained through Chi-Square test unless otherwise specified. [b]Fisher's Exact Test was used for variables with small counts (n<5). Agree or strongly agree/good or excellent was scored from 7 to 10; neutral was scored from 4 to 6; and disagree or strongly disagree/poor was scored from 0 to 3.

**Table 2.2:** 2009 NCI EX vs. 2018 NCI Current EX

| Characteristic | 2009 NCI (n=51) No. (%) | 2018 NCI Current (n=40) No. (%) | Odds Ratio (95% CI)[a] | *P*[a] |
|---|---|---|---|---|
| **Attitudes towards Palliative Care Integration** | | | | |
| A stronger integration of palliative care services into oncology practice will benefit patients at my institution | 46 (90.2%) | 35 (89.7%) | 0.94 (0.23, 3.88) | 0.93 |
| More research funding should be directed towards palliative care services | 43 (84.3%) | 34 (87.2%) | 1.28 (0.41, 4.00) | 0.67 |
| My institution will be increasing the number of palliative care physicians over the next 5y | 28 (56.0%) | 28 (70.0%) | 1.99 (0.88, 4.49) | 0.10 |
| My institution will be increasing the number of palliative care mid-level providers (advanced nurse practitioners, physician assistants) over the next 5y | 30 (58.8%) | 26 (65.0%) | 1.45 (0.65, 3.21) | 0.36 |
| My institution will be increasing the number of palliative care staff nurses over the next 5y | 26 (52.0%) | 19 (47.5%) | 0.88 (0.40, 1.97) | 0.76 |
| My institution will be increasing the number of palliative care acute beds over the next 5y | 16 (32.7%) | 10 (25.6%) | 0.75 (0.38, 1.48) | 0.40 |
| My institution will be increasing the funding for palliative care over the next 5y | 22 (44.0%) | 21 (52.5%) | 1.49 (0.67, 3.33) | 0.33 |
| **Barriers to Palliative Care Access** | | | | |
| Limited palliative care needs in my institution | 3 (5.9%) | 1 (2.6%) | 0.45 (0.05, 4.01) | 0.47 |
| Limited institutional budget for palliative care services | 36 (70.6%) | 22 (57.9%) | 0.48 (0.25, 0.95) | 0.03 |
| Poor reimbursement for palliative care services | 38 (74.5%) | 21 (55.3%) | 0.34 (0.16, 0.74) | 0.01 |
| Lack of adequately trained palliative care physicians and nurses | 14 (27.5%) | 20 (52.6%) | 2.93 (1.21, 7.10) | 0.02 |
| Lack of evidence to suggest palliative care improves patient outcomes | 4 (7.8%) | 1 (2.6%) | 0.33 (0.04, 2.61) | 0.29 |
| Concern that palliative care may increase hospital mortality | 6 (11.8%) | 3 (7.9%) | 0.64 (0.15, 2.74) | 0.55 |
| Palliative care may negatively impact my institution's national rating | 4 (7.8%) | 1 (2.6%) | 0.32 (0.04, 2.85) | 0.31 |
| Palliative care is available at my institution but not utilized frequently | 9 (17.6%) | 8 (21.1%) | 1.26 (0.48, 3.33) | 0.64 |
| Other | 11 (21.6%) | 1 (2.6%) | 0.11 (0.02, 0.73) | 0.02 |
| **Self-Assessments** | | | | |
| Pain management services 5y ago | 25 (49.0%) | 14 (35.9%) | 0.59 (0.25, 1.39) | 0.23 |
| Pain management services now | 45 (88.2%) | 28 (71.8%) | 0.31 (0.10, 1.02) | 0.05 |
| Palliative care services 5y ago | 15 (30.0%) | 12 (30.8%) | 1.04 (0.42, 2.58) | 0.93 |
| Palliative care services now | 40 (80.0%) | 35 (89.7%) | 2.15 (0.61, 7.57) | 0.23 |

Note: Abbreviations: NCI, National Cancer Institute; EX, executive. Respondents specified their degree of agreement using a 0-10 numeric rating scale from 'strongly disagree' to 'strongly agree' for attitudes; and 'poor' to 'excellent' for self-assessments.
[a]Logistic regression via a generalized estimating equation was used to examine the change in each variable between 2009 NCI cohort and the 2018 NCI Current Cohort. All Attitudes and Beliefs & Self-Assessments were originally ordinal variables and recoded as dichotomous: Agree or strongly agree was scored from 7 to 10; neutral (originally 4 to 6) was grouped with disagree or strongly disagree (originally 0 to 3) and was scored from 0 to 6. All Barriers to Palliative Access variables were dichotomous.

**Table 2.3:** 2009 Non-NCI EX vs. 2018 Non-NCI Current EX

| Characteristic | 2009 Non-NCI (n=50) No. (%) | 2018 Non-NCI Current (n=40) No. (%) | Odds Ratio (95% CI)[a] | *P*[a] |
|---|---|---|---|---|
| **Attitudes towards Palliative Care Integration** | | | | |
| A stronger integration of palliative care services into oncology practice will benefit patients at my institution | 44 (91.7%) | 36 (90.0%) | 0.82 (0.19, 3.50) | 0.79 |
| More research funding should be directed towards palliative care services | 39 (81.3%) | 32 (80.0%) | 0.92 (0.32, 2.67) | 0.88 |
| My institution will be increasing the number of palliative care physicians over the next 5y | 12 (25.5%) | 15 (37.5%) | 1.75 (0.70, 4.38) | 0.23 |
| My institution will be increasing the number of palliative care mid-level providers (advanced nurse practitioners, physician assistants) over the next 5y | 15 (32.6%) | 21 (52.5%) | 2.28 (0.95, 5.48) | 0.06 |
| My institution will be increasing the number of palliative care staff nurses over the next 5y | 13 (27.1%) | 16 (41.0%) | 1.87 (0.76, 4.61) | 0.17 |
| My institution will be increasing the number of palliative care acute beds over the next 5y | 8 (16.7%) | 7 (17.9%) | 1.09 (0.36, 3.34) | 0.87 |
| My institution will be increasing the funding for palliative care over the next 5y | 11 (22.9%) | 9 (23.1%) | 1.01 (0.37, 2.75) | >0.99 |
| **Barriers to Palliative Care Access** | | | | |
| Limited palliative care needs in my institution | 3 (6.0%) | 3 (7.7%) | 1.31 (0.25, 6.85) | 0.75 |
| Limited institutional budget for palliative care services | 26 (52.0%) | 23 (59.0%) | 1.33 (0.57, 3.09) | 0.51 |
| Poor reimbursement for palliative care services | 25 (50.0%) | 17 (43.6%) | 0.77 (0.33, 1.79) | 0.55 |
| Lack of adequately trained palliative care physicians and nurses | 25 (50.0%) | 17 (43.6%) | 0.77 (0.33, 1.79) | 0.55 |
| Lack of evidence to suggest palliative care improves patient outcomes[b] | 2 (4.0%) | 0 (0.0%) | - | - |
| Concern that palliative care may increase hospital mortality | 4 (8.0%) | 4 (10.3%) | 1.31 (0.31, 5.63) | 0.71 |
| Palliative care may negatively impact my institution's national rating[b] | 0 (0.0%) | 2 (5.1%) | - | - |
| Palliative care is available at my institution but not utilized frequently | 9 (18.0%) | 14 (35.9%) | 2.55 (0.96, 6.76) | 0.06 |
| Other | 11 (22.0%) | 1 (2.6%) | 0.09 (0.01, 0.76) | 0.03 |
| **Self-Assessments** | | | | |
| Pain management services 5y ago | 18 (39.1%) | 12 (30.8%) | 0.69 (0.28, 1.70) | 0.42 |
| Pain management services now | 37 (77.1%) | 33 (82.5%) | 1.40 (0.49, 4.04) | 0.53 |
| Palliative care services 5y ago | 9 (20.5%) | 11 (29.7%) | 1.65 (0.60, 4.55) | 0.34 |
| Palliative care services now | 27 (57.4%) | 28 (71.8%) | 1.89 (0.76, 4.67) | 0.17 |

Abbreviations: NCI, National Cancer Institute; EX, executive. Respondents specified their degree of agreement using a 0-10 numeric rating scale from 'strongly disagree' to 'strongly agree' for attitudes; and 'poor' to 'excellent' for self-assessments.
[a]Logistic regression was used to examine the change in each variable between the 2009 Non-NCI cohort and the 2018 Non-NCI Current cohort.
[b]Odds ratios and p values could not be obtained because of extreme values.
All Attitudes and Beliefs & Self-Assessments were originally ordinal variables and recoded as dichotomous: Agree or strongly agree was scored from 7 to 10; neutral (originally 4 to 6) was grouped with disagree or strongly disagree (originally 0 to 3) and was scored from 0 to 6. All Barriers to Palliative Access variables were dichotomous.

**Table 2.4:** Comparison of Studies: Palliative Care Attitudes and Self-Assessments

| STUDY | Davis et al., 2015[9] | | | | | Hui et al., 2010[8] | | This Study | |
|---|---|---|---|---|---|---|---|---|---|
| CHARACTERISTIC | Overall | NCI Centers (n=19) | ESMO Centers (n=34) | Other cancer centers (n=66) | Urban hospitals/clinics (n=45) | NCI Cancer Centers (n=51) No. (%) | Non-NCI Cancer Centers (n=50) No. (%) | 2018 NCI Centers (n=40) No. (%) | 2018 Non-NCI Centers (n=40) No. (%) |
| **Attitudes towards Palliative Care Integration** | | | | | | | | | |
| "A stronger integration of PC into oncology practice will benefit patients at my institution." | 140 (87 %) | 16 (84 %) | 30 (88 %) | 58 (91 %) | 36 (82 %) | 46 (90%) | 44 (92%) | 35 (89.7%) | 36 (90.0%) |
| "More research funding should be directed toward PC." | 129 (80 %) | 16 (84 %) | 31 (91 %) | 51 (81 %) | 31 (69 %) | 43 (84%) | 39 (81%) | 34 (87.2%) | 32 (80.0%) |
| "Will your institution be increasing the number of PC M.D.s over the next 5 years?" | 46 (30 %) | 6 (35 %) | 13 (39 %) | 22 (36 %) | 5 (12 %) | 28 (56%) | 12 (25%) | 28 (70.0%) | 15 (37.5%) |
| "Will your institution be increasing the number of PC mid-level providers over the next 5 years?" | 45 (29 %) | 7 (41 %) | 12 (36 %) | 18 (30 %) | 8 (19 %) | 30 (59%) | 15 (33%) | 26 (65.0%) | 21 (52.5%) |
| "Will your institution be increasing the number of PC nurses over the next 5 years?" | 38 (25 %) | 3 (18 %) | 12 (36 %) | 17 (29 %) | 9 (14 %) | 26 (52%) | 13 (27%) | 19 (47.5%) | 16 (41.0%) |
| "Will your institution be increasing the number of PC acute beds over the next 5 years" ? | 28 (18 %) | 0 (0%) | 11 (33 %) | 10 (17 %) | 7 (16 %) | 16 (33%) | 8 (17%) | 10 (25.6%) | 7 (17.9%) |
| "Will your institution be increasing funding for PC over the next 5 years?" | 26 (17 %) | 3 (18 %) | 9 (28 %) | 10 (17 %) | 4 (9 %) | 22 (44%) | 11 (23%) | 21 (52.5%) | 9 (23.1%) |
| **Self-Assessments** | | | | | | | | | |
| Overall effectiveness of pain management services 5 years ago | 45 (28 %) | 6 (32 %) | 11 (32 %) | 19 (31 %) | 9 (21 %) | 25 (49%) | 18 (39%) | 14 (35.9%) | 12 (30.8%) |
| Overall effectiveness of pain management services today | 97 (62 %) | 10 (56 %) | 26 (79 %) | 38 (60 %) | 23 (53 %) | 45 (88%) | 37 (77%) | 28 (71.8%) | 33 (82.5%) |
| Quality of PC provided 5-years ago | 38 (24 %) | 1 (5 %) | 11 (32 %) | 17 (27 %) | 9 (20 %) | 15 (30%) | 9 (20%) | 12 (30.8%) | 11 (29.7%) |
| Quality of PC currently provided | 83 (53 %) | 12 (63 %) | 24 (71 %) | 33 (53 %) | 14 (33 %) | 40 (80%) | 27 (57%) | 35 (89.7%) | 28 (71.8%) |

**Table 2.5:** 2009 NCI EX vs. 2018 NCI Previous EX

| Characteristic | 2009 NCI (n=51) No. (%) | 2018 NCI Previous (n=49) No. (%) | Odds Ratio (95% CI)[a] | *P*[a] |
|---|---|---|---|---|
| **Attitudes towards Palliative Care Integration** | | | | |
| A stronger integration of palliative care services into oncology practice will benefit patients at my institution | 46 (90.2%) | 45 (93.8%) | 1.60 (0.35, 7.28) | 0.55 |
| More research funding should be directed towards palliative care services | 43 (84.3%) | 42 (87.5%) | 1.33 (0.47, 3.76) | 0.60 |
| My institution will be increasing the number of palliative care physicians over the next 5y | 28 (56.0%) | 31 (63.3%) | 1.47 (0.71, 3.04) | 0.30 |
| My institution will be increasing the number of palliative care mid-level providers (advanced nurse practitioners, physician assistants) over the next 5y | 30 (58.8%) | 29 (59.2%) | 1.13 (0.54, 2.38) | 0.74 |
| My institution will be increasing the number of palliative care staff nurses over the next 5y | 26 (52.0%) | 21 (42.9%) | 0.71 (0.33, 1.55) | 0.39 |
| My institution will be increasing the number of palliative care acute beds over the next 5y | 16 (32.7%) | 9 (18.8%) | 0.53 (0.23, 1.21) | 0.13 |
| My institution will be increasing the funding for palliative care over the next 5y | 22 (44.0%) | 25 (51.0%) | 1.37 (0.63, 2.98) | 0.42 |
| **Barriers to Palliative Care Access** | | | | |
| Limited palliative care needs in my institution | 3 (5.9%) | 2 (4.3%) | 0.76 (0.13, 4.54) | 0.76 |
| Limited institutional budget for palliative care services | 36 (70.6%) | 28 (59.6%) | 0.53 (0.29, 0.94) | 0.03 |
| Poor reimbursement for palliative care services | 38 (74.5%) | 25 (53.2%) | 0.33 (0.17, 0.67) | <0.01 |
| Lack of adequately trained palliative care physicians and nurses | 14 (27.5%) | 25 (53.2%) | 3.21 (1.33, 7.78) | 0.01 |
| Lack of evidence to suggest palliative care improves patient outcomes | 4 (7.8%) | 1 (2.1%) | 0.27 (0.03, 2.10) | 0.21 |
| Concern that palliative care may increase hospital mortality | 6 (11.8%) | 3 (6.4%) | 0.51 (0.12, 2.15) | 0.36 |
| Palliative care may negatively impact my institution's national rating | 4 (7.8%) | 1 (2.1%) | 0.26 (0.03, 2.26) | 0.22 |
| Palliative care is available at my institution but not utilized frequently | 9 (17.6%) | 11 (23.4%) | 1.45 (0.60, 3.51) | 0.41 |
| Other | 11 (21.6%) | 2 (4.3%) | 0.17 (0.04, 0.80) | 0.03 |
| **Self-Assessments** | | | | |
| Pain management services 5y ago | 25 (49.0%) | 16 (33.3%) | 0.52 (0.23, 1.17) | 0.11 |
| Pain management services now | 45 (88.2%) | 37 (77.1%) | 0.41 (0.13, 1.31) | 0.13 |
| Palliative care services 5y ago | 15 (30.0%) | 15 (31.3%) | 1.06 (0.45, 2.53) | 0.89 |
| Palliative care services now | 40 (80.0%) | 44 (91.7%) | 2.71 (0.78, 9.46) | 0.12 |

Abbreviations: NCI, National Cancer Institute; EX, executive. Respondents specified their degree of agreement using a 0-10 numeric rating scale from 'strongly disagree' to 'strongly agree' for attitudes; and 'poor' to 'excellent' for self-assessments.
[a]Logistic regression via a generalized estimating equation was used to examine the change in each variable between 2009 NCI cohort and the 2018 NCI Previous Cohort.
All Attitudes and Beliefs & Self-Assessments were originally ordinal variables and recoded as dichotomous: Agree or strongly agree was scored from 7 to 10; neutral (originally 4 to 6) was grouped with disagree or strongly disagree (originally 0 to 3) and was scored from 0 to 6. All Barriers to Palliative Access variables were dichotomous.

**Table 2.6:** 2009 Non-NCI EX vs. 2018 Non-NCI Previous EX

| Characteristic | 2009 Non-NCI (n=50) No. (%) | 2018 Non-NCI Previous (n=48) No. (%) | Odds Ratio (95% CI)[a] | *P*[a] |
|---|---|---|---|---|
| **Attitudes towards Palliative Care Integration** | | | | |
| A stronger integration of palliative care services into oncology practice will benefit patients at my institution[b] | 44 (91.7%) | 48 (100.0%) | - | - |
| More research funding should be directed towards palliative care services | 39 (81.3%) | 45 (93.8%) | 3.73 (0.87, 16.05) | 0.08 |
| My institution will be increasing the number of palliative care physicians over the next 5y | 12 (25.5%) | 18 (37.5%) | 1.69 (0.78, 3.67) | 0.18 |
| My institution will be increasing the number of palliative care mid-level providers (advanced nurse practitioners, physician assistants) over the next 5y | 15 (32.6%) | 29 (60.4%) | 3.18 (1.48, 6.80) | 0.003 |
| My institution will be increasing the number of palliative care staff nurses over the next 5y | 13 (27.1%) | 17 (35.4%) | 1.50 (0.63, 3.60) | 0.36 |
| My institution will be increasing the number of palliative care acute beds over the next 5y | 8 (16.7%) | 8 (16.7%) | 1.14 (0.37, 3.47) | 0.82 |
| My institution will be increasing the funding for palliative care over the next 5y | 11 (22.9%) | 18 (37.5%) | 1.81 (0.77, 4.23) | 0.17 |
| **Barriers to Palliative Care Access** | | | | |
| Limited palliative care needs in my institution[b] | 3 (6.0%) | 0 (0.0%) | - | - |
| Limited institutional budget for palliative care services | 26 (52.0%) | 22 (47.8%) | 0.86 (0.38, 1.95) | 0.71 |
| Poor reimbursement for palliative care services | 25 (50.0%) | 23 (50.0%) | 0.98 (0.43, 2.19) | 0.95 |
| Lack of adequately trained palliative care physicians and nurses | 25 (50.0%) | 22 (47.8%) | 0.91 (0.41, 2.04) | 0.82 |
| Lack of evidence to suggest palliative care improves patient outcomes | 2 (4.0%) | 1 (2.2%) | 0.53 (0.05, 5.79) | 0.60 |
| Concern that palliative care may increase hospital mortality | 4 (8.0%) | 3 (6.5%) | 0.81 (0.17, 3.96) | 0.80 |
| Palliative care may negatively impact my institution's national rating[b] | 0 (0.0%) | 3 (6.5%) | - | - |
| Palliative care is available at my institution but not utilized frequently | 9 (18.0%) | 17 (37.0%) | 2.61 (1.00, 6.82) | 0.05 |
| Other | 11 (22.0%) | 2 (4.3%) | 0.18 (0.04, 0.79) | 0.02 |
| **Self-Assessments** | | | | |
| Pain management services 5y ago | 18 (39.1%) | 22 (45.8%) | 1.32 (0.59, 2.96) | 0.50 |
| Pain management services now | 37 (77.1%) | 39 (81.3%) | 1.22 (0.43, 3.43) | 0.71 |
| Palliative care services 5y ago | 9 (20.5%) | 12 (26.1%) | 1.37 (0.51, 3.67) | 0.54 |
| Palliative care services now | 27 (57.4%) | 39 (83.0%) | 4.12 (1.71, 9.96) | 0.002 |

Abbreviations: NCI, National Cancer Institute; EX, executive. Respondents specified their degree of agreement using a 0-10 numeric rating scale from 'strongly disagree' to 'strongly agree' for attitudes; and 'poor' to 'excellent' for self-assessments.
[a]Logistic regression via a generalized estimating equation was used to examine the change in each variable between 2009 Non-NCI cohort and the 2018 Non-NCI Previous cohort.
[b]Odds ratio and p-values could not be generated because of extreme values.
All Attitudes and Beliefs & Self-Assessments were originally ordinal variables and recoded as dichotomous: Agree or strongly agree was scored from 7 to 10; neutral (originally 4 to 6) was grouped with disagree or strongly disagree (originally 0 to 3) and was scored from 0 to 6. All Barriers to Palliative Access variables were dichotomous.

# CONCLUSION

In this study, program leaders and executives among cancer centers in the United States were surveyed to provide perspectives about palliative care from an operational and institutional level point of view, respectively. We found that NCI-designated cancer centers were more likely to have an interdisciplinary palliative care team than non-NCI-designated cancer centers. We also found that cancer center executives endorsed the integration of palliative care into standard oncologic care, with NCI-designated cancer centers more willing to invest in their palliative care programs. Over the last decade, numerous studies continue to show benefits of improved symptoms and quality of life associated with early incorporation of palliative care early into the traditional cancer treatment timeline. While barriers to palliative care access continue to be financial and workforce-related, executives need to balance institutional priorities even with their support for palliative care integration. In the meanwhile, more educational and training opportunities need to exist to train the next generation palliative care workforce. More resources are needed to further develop palliative care programs and to meet expected demands from an aging population.

# APPENDICES

**Appendix 1**: 2018 National Survey of PC Services at US Cancer Centers: Program Leaders

THE UNIVERSITY OF TEXAS
MD Anderson Cancer Center
Making Cancer History®

## National Survey of Palliative Care Services at US Cancer Centers: Program Leaders

Thank you for participating in this survey. Please try to complete the following survey in one sitting. It should take no more than **15-20 minutes**. When answering questions regarding numbers or percentages, please use **approximations** (i.e. we do not expect you to look up the information in detail). Thank you!

**I. Palliative Medicine Services**

A. Type of cancer center:
- ☐ NCI designated comprehensive cancer center
- ☐ NCI designated clinical cancer center
- ☐ Non-NCI designated cancer center

B. Does your institution provide any palliative care services?
- ☐ Yes (please complete this section)
- ☐ No (please skip to Section V)

C. What is the name of your palliative care program? (Check all that apply)
- ☐ Comprehensive cancer care
- ☐ Pain and symptom management
- ☐ Palliative care
- ☐ Supportive care
- ☐ Other: _____

D. How long **approximately** has your palliative care program been officially seeing patients?

☐ <1 year ☐ 1-2 years ☐ 3-5 years ☐ >5 years

E. What are the specific kinds of palliative care services that are available? (Check all that apply)
- ☐ Palliative care consultation/mobile team service
- ☐ Palliative care/supportive care clinic
- ☐ Dedicated palliative care acute care beds
- ☐ Institution operated hospice

F. What are the type(s) of services that your palliative care team offers? (Check all that apply)
- ☐ Assessment and management of psychiatric disorders
- ☐ Assistance in obtaining advance directives and DNR's
- ☐ Assistance in resolving complicated ethical issues
- ☐ Assistance with referrals to hospice, home care, or other placements
- ☐ Comprehensive care plan for those requiring comfort care
- ☐ Pain consultation
- ☐ Psychosocial support
- ☐ Symptom management

G. **Approximately**, what proportion of patients seen by palliative care belong to the pediatric age group (<18 year old)?

☐ 0% ☐ 1-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%

*ID:* _____ 1

# National Survey of Palliative Care Services at US Cancer Centers: Program Leaders

**I. Palliative Medicine Services (continued)**

H. What is the professional background of the palliative care program leader? (Check all that apply)

- ☐ Anesthesia
- ☐ Family medicine
- ☐ Internal medicine
- ☐ Medical Oncology
- ☐ Nursing
- ☐ Palliative medicine
- ☐ Pediatrics
- ☐ Psychiatry
- ☐ Radiation Oncology
- ☐ Surgery
- ☐ Other: _____

I. Within your program, please indicate with a check mark the **approximate** number of paid personnel assigned to palliative care:

| **Personnel** | 0 | 1-5 | 6-10 | 11-25 | 26-50 | >50 |
|---|---|---|---|---|---|---|
| Ward nurses (inpatient) | | | | | | |
| Clinic nurses (outpatient) | | | | | | |

| **Personnel** | 0 | 1 | 2-5 | 6-10 | >10 |
|---|---|---|---|---|---|
| Chaplains | | | | | |
| Dieticians | | | | | |
| Mid-level providers (advanced nurse practitioners or physician assistants) | | | | | |
| Palliative care physicians | | | | | |
| Rehab (PT/OT) | | | | | |
| Pharmacists | | | | | |
| Psychiatrists | | | | | |
| Psychologists/counselors | | | | | |
| Social workers | | | | | |
| Other | | | | | |

J. **Approximately**, how many full-time equivalent (FTE) physician positions are available in your palliative care program?

☐

K. **Approximately**, how many physicians on your palliative care team have at least 20% academic protected time?

☐

L. Does your palliative care program require physicians to be certified by the American Board of Hospice and Palliative Medicine or American Board of Medical Specialties?

☐ Yes ☐ No

M. Does your palliative care program require nurses to be certified by the National Board for Certification of Hospice and Palliative Nurses?

☐ Yes ☐ No

*ID:* _____ 2

# National Survey of Palliative Care Services at US Cancer Centers: Program Leaders

**I. Palliative Medicine Services (continued)**

N. On average, how long does your palliative care team follow patients in your institution (all inpatient and outpatient encounters)?

☐ 1-7 days ☐ >1-4 weeks ☐ >1-12 months ☐ >1-2 years ☐ >2 years

**II. Palliative Care Outpatient Clinic**

A. Does your palliative care program see patients in the outpatient setting? (Check all that apply)

☐ Yes, we have a dedicated palliative care outpatient clinic (please complete this section)
☐ Yes, we see patients in oncology clinics i.e. embedded (please complete this section)
☐ No (please skip to Section III)

B. **Approximately**, how many days per week is it held? _____

C. **Approximately**, how many referrals per month? _____

D. **Approximate** number of days from referral to death (if available)? _____

E. Referral sources: (Check all that apply)

☐ Emergency Department ☐ Medical Oncology ☐ Surgery
☐ Hematology ☐ Radiation Oncology ☐ Other: _____

**III. Inpatient Palliative Care Units/Beds**

A. Does your palliative care program have any dedicated acute care beds in your institution **(NON-HOSPICE)**?

☐ Yes (please complete this section) ☐ No (please skip to Section IV)

B. Number of designated palliative care beds: _____

C. Is there a physical unit designated as the palliative care unit (PCU) and primarily for palliative care inpatients?

☐ Yes ☐ No

D. How long has your inpatient palliative care service been in place?

☐ <6 months ☐ 6 months-11 months ☐ 1-2 years ☐ 3-5 years ☐ >5 years

E. **Approximate** number of inpatient palliative care discharges per month? _____

F. **Approximate** median duration of inpatient palliative care stay (days)? _____

G. **Approximate** median days from admission to death (if available)? _____

H. **Approximate** inpatient palliative care mortality rate (i.e. [death] / [total admissions])? _____%

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**III. Inpatient Palliative Care Units/Beds (continued)**

I. Please indicate the **approximate** percentages for each potential reason for admission.

1. Because they are imminently dying? _____%
2. For acute symptom management? _____%
3. For psychosocial reasons? _____%
4. For respite? _____%
5. Due to other reason(s) not mentioned above? _____%
   a. Explain other reason(s): _____

J. Please indicate the **approximate** percentages of referral sources to your palliative care service.

1. Intensive care unit? _____%
2. Other inpatient units? _____%
3. Emergency room? _____%
4. Outpatient clinics? _____%
5. Other hospitals? _____%
6. Hospice? _____%
7. Other, _____%. Please specify, _____

K. **Approximately**, what proportion of patients receive regular psychosocial assessments on each admission?

☐ 0% ☐ 1-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%

L. **Approximately**, what proportion of inpatients have family conferences during admissions?

☐ 0% ☐ 1-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%

M. **Approximately**, how often do primary oncologists attend these family conferences?

☐ 0% ☐ 1-25% ☐ 26-50% ☐ 51-75% ☐ 76-100%

N. **Approximately**, what proportion of inpatients have Do-Not-Resuscitate orders?

☐ 0% ☐ 1-25% ☐ 26-50% ☐ 51-75% ☐ 76-99% ☐ 100%

**IV. Consultation Service**

A. Does your palliative care program have a dedicated consultation service in your institution?

☐ Yes (please complete this section)
☐ No (please skip to Section V)

B. How often is it available?

☐ 24 hours/7 days per week ☐ 24 hours/weekdays only
☐ Business hours/weekdays only ☐ Other: _____

C. **Approximately**, how many referrals per month? _____

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**IV. Consultation Service (continued)**

D. **Approximately**, how many days from referral to death? _____

E. Referral sources: (Check all that apply)

☐ Emergency Department ☐ Medical Oncology ☐ Surgery
☐ Hematology ☐ Radiation Oncology ☐ Other: _____

**V. Hospice**

A. Does your institution operate a hospice? ☐ Yes ☐ No

If yes, please indicate the **approximate** average hospice daily census: _____

**VI. Educational Services Targeting Palliative Care**

A. Fellowship program for Palliative Medicine? ☐ Yes ☐ No

If yes, **approximate** number of clinical fellows per year: _____

If yes, **approximate** number of research fellows per year: _____

B. Mandatory palliative care rotations for…

| | | | |
|---|---|---|---|
| Medical oncology/hematology fellows | ☐ Yes | ☐ No | ☐ Not applicable |
| Radiation oncology fellows | ☐ Yes | ☐ No | ☐ Not applicable |
| Pediatric oncology fellows | ☐ Yes | ☐ No | ☐ Not applicable |
| Medical students | ☐ Yes | ☐ No | ☐ Not applicable |
| Other residents or fellows:_____ | ☐ Yes | ☐ No | ☐ Not applicable |

C. Training of mid-level providers in palliative care: ☐ Yes ☐ No

D. Dedicated palliative care grand rounds: ☐ Yes ☐ No

If yes, how many times per week: ☐ 1 ☐ 2 ☐ 3 or more

If yes, regularly attended by oncologists: ☐ Yes ☐ No

E. Didactic palliative care curriculum for oncology fellows provided by palliative care teams
☐ Yes ☐ No

F. Continuing medical education in palliative care for attending oncologists
☐ Yes ☐ No

G. Combined palliative care and oncology educational activities for fellows/trainees
☐ Yes ☐ No

*ID:* _____ 5

**VII. Research in Palliative Care**

A. Is there a research program in palliative care?

- ☐ Yes (please complete this section)
- ☐ No (please skip to section VIII)

B. The research team consists of… (Check all that apply)

| | | |
|---|---|---|
| ☐ Chaplains | ☐ Pharmacists | ☐ Rehab therapists (PT/OT) |
| ☐ Data analysts | ☐ Physicians | ☐ Research nurses |
| ☐ Dieticians | ☐ Psychologists | ☐ Social workers |

C. Outside funding: ☐ Yes ☐ No

If yes, source(s) of funding: (Check all that apply)

- ☐ Private industry
- ☐ Institution
- ☐ Peer reviewed (NIH, ACS, etc)
- ☐ Private foundation/philanthropy

D. Please indicate the types of palliative care studies conducted over the last year: (Check all that apply)

- ☐ Prospective randomized therapeutic trials
- ☐ Prospective randomized non-therapeutic trials
- ☐ Other prospective non-randomized studies
- ☐ Retrospective studies
- ☐ Case series/case reports
- ☐ Qualitative studies
- ☐ Others. Please specify, _____
- ☐ None

E. Please indicate the **approximate** number of abstracts presented at meetings by your department last year:

| | | | | | |
|---|---|---|---|---|---|
| Oncology conferences (e.g. ASCO) | ☐ 0 | ☐ 1-2 | ☐ 3-5 | ☐ 6-10 | ☐ >10 |
| Palliative care conferences (e.g. AAHPM) | ☐ 0 | ☐ 1-2 | ☐ 3-5 | ☐ 6-10 | ☐ >10 |
| Others | ☐ 0 | ☐ 1-2 | ☐ 3-5 | ☐ 6-10 | ☐ >10 |

F. Please indicate the **approximate** number of papers published by your department last year:

| | | | | | |
|---|---|---|---|---|---|
| Oncology journals (e.g. JCO, JNCI) | ☐ 0 | ☐ 1-2 | ☐ 3-5 | ☐ 6-10 | ☐ >10 |
| Palliative care journals (e.g. J Pall Med) | ☐ 0 | ☐ 1-2 | ☐ 3-5 | ☐ 6-10 | ☐ >10 |
| General medical journals (e.g. NEJM, JAMA) | ☐ 0 | ☐ 1-2 | ☐ 3-5 | ☐ 6-10 | ☐ >10 |

**Appendix 2**: 2018 National Survey of PC Services at US Cancer Centers: Executives

THE UNIVERSITY OF TEXAS
MD Anderson Cancer Center
Making Cancer History®

## National Survey of Palliative Care Services at US Cancer Centers: Executives

Thank you for participating in this survey. Please try to complete the following survey in one sitting. It should take no more than **5 minutes**. When answering questions regarding numbers or percentages, please use **approximations** (i.e. we do not expect you to look up the information in detail). Thank you!

**I. Center Characteristics**

A. Type of cancer center:

- ☐ NCI designated comprehensive cancer center
- ☐ NCI designated clinical cancer center
- ☐ Non-NCI designated cancer center

**II. Palliative Care Access**

A. Has palliative care been available at your institution anytime over the last 10 years?

- ☐ Yes (please go to question B)
- ☐ No (please go to question F)

B. Is it currently active?

- ☐ Yes (please go to question C)
- ☐ No (please go to question F)

C. Please indicate the profession of the palliative care program leader at your institution:

- ☐ Physician
- ☐ Advanced nurse practitioner
- ☐ Other. Please specify _____

D. Are there any palliative care physicians currently at your institution?

- ☐ Yes
- ☐ No

E. What are the specific kinds of palliative care services available? (check all that apply)

- ☐ Palliative care consultation/mobile team service
- ☐ Palliative care/supportive care clinic
- ☐ Dedicated palliative care acute care beds
- ☐ Institution-operated hospice

F. Irrespective of whether palliative care is offered at your institution, what in your opinion, are some of the potential barriers to palliative care access for your institution? (check all that apply)

- ☐ Limited palliative care needs in my institution
- ☐ Limited institutional budget for palliative care services
- ☐ Poor reimbursement for palliative care services
- ☐ Lack of adequately trained palliative care physicians and nurses
- ☐ Lack of evidence to suggest palliative care improves patient outcomes
- ☐ Concern that palliative care may increase hospital mortality
- ☐ Palliative care may negatively impact my institution's national rating (e.g. in *US News and World Report*)
- ☐ Palliative care is available at my institution but not utilized frequently
- ☐ Other _____

*ID:*____ 1

## III. Overall Assessment and Attitudes

A. How would you rate the overall effectiveness of your pain management services 5 years ago?

| Poor | | | | | Neutral | | | | | Excellent |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

B. How would you rate the overall effectiveness of your pain management services today?

| Poor | | | | | Neutral | | | | | Excellent |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

C. How would you rate the overall palliative care services provided at your institution 5 years ago?

| Poor | | | | | Neutral | | | | | Excellent |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

D. How would you rate the overall palliative care services provided at your institution today?

| Poor | | | | | Neutral | | | | | Excellent |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

E. Please indicate whether you agree with the following statement: "A stronger integration of palliative care services into oncology practice will benefit patients at my institution."

| Strongly disagree | | | | | Neutral | | | | | Strongly agree |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

F. Please indicate whether you agree with the following statement: "More research funding should be directed towards palliative care services."

| Strongly disagree | | | | | Neutral | | | | | Strongly agree |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

G. Will your institution be increasing the number of palliative care physicians over the next 5 years?

| Definitely No | | | | | Unsure | | | | | Definitely Yes |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

H. Will your institution be increasing the number of palliative care mid-level providers (advanced nurse practitioners, physician assistants) over the next 5 years?

| Definitely No | | | | | Unsure | | | | | Definitely Yes |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

*ID:*____

**III. Overall Assessment and Attitudes (continued)**

I. Will your institution be increasing the number of palliative care staff nurses over the next 5 years?

| Definitely No | | | | | Unsure | | | | Definitely Yes | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

J. Will your institution be increasing the number of palliative care acute beds over the next 5 years?

| Definitely No | | | | | Unsure | | | | Definitely Yes | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

K. Will your institution be increasing the funding for palliative care over the next 5 years?

| Definitely No | | | | | Unsure | | | | Definitely Yes | |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

**IV. Center Information**

Please provide **approximations** for the following questions (i.e. we do not expect you to look up the information in detail). If this information is not readily available, please leave it blank and return the survey. Thank you.

A. **Approximate** number of outpatients seen in 2017: _____

B. Inpatient beds dedicated to cancer care? ☐ Yes ☐ No

If yes…Please indicate the **approximate** number of inpatient beds at your institution: _____

Please indicate the **approximate** number of admissions in 2017: _____

Please indicate the **approximate** number of inpatient deaths in 2017: _____

Comments: _____

_____

_____

Thank you for your participation!

*ID:*____

## VIII. Oncology Services

The following questions pertain to the outpatient oncology patient population and may provide information on the degree of integration of palliative care into a cancer center. Please provide **approximations** for the following questions (i.e. we do not expect you to look up the information in detail). If this information is not readily available, please leave it blank and return the survey. Thank you.

A. Is symptom screening routinely conducted in the outpatient oncology clinics at your institution?

- ☐ Yes, all oncology clinics have routine symptom screening
- ☐ Yes, some oncology clinics have routine symptom screening
- ☐ No

B. **Approximately,** what proportion of patients with advanced cancer seen at the outpatient oncology clinics have advance care plans (e.g. medical power of attorney, living will) documented in the medical chart (if available)?

_____ %

The following questions pertain to the general cancer patient population at your hospital.

C. **Approximately** what proportion of cancer outpatients at your hospital have pain ASSESSED on either of the last two visits before death (if available)? _____ %

D. **Approximately** what proportion of cancer patients at your hospital have 2 or more emergency room visits in last 30 days of life (if available)?

_____ %

E. **Approximately** what proportion of cancer patients' place of death is consistent with their preference (if available)?

_____ %

Comments: _____

_____

**We greatly appreciate your time and effort completing this survey and returning it back to us. Thank you!**

*ID:* _____ 7

**Appendix 3**: UTHealth IRB Approval Letter


Office of Academic Affairs and Student Services

**MEMORANDUM**

**TO:** Joseph Chen

**FROM:** Nesh Aqrawi
Director for Academic Affairs

**RE:** Dissertation Proposal

**DATE:** January 4, 2020

**TITLE:** A Comparison of Interdisciplinary Palliative Care Teams and Leadership Attitudes of NCI and Non-NCI Centers Towards Palliative Care in the United States from 2009-2018

Your proposal has been reviewed and approved by The University of Texas School of Public Health at Houston Office of Academic Affairs and Student Services. Your proposal was determined to be exempt by The University of Texas Health Science Center at Houston (UTHealth) Committee for the
Protection of Human Subjects as study # HSC-SPH-19-1056. You may proceed with your research.

Cc: Paige Padgett Wermuth, PhD
David Hui, MD
Shiva Dibaj, PhD
David Lairson, PhD
Frances Lee Revere, PhD

**Appendix 4**: The University of Texas MD Anderson Cancer Center IRB Approval Letter

THE UNIVERSITY OF TEXAS
MD Anderson Cancer Center
**Office of Protocol Research**

Institutional Review Board (IRB)
Unit 1637
Phone 713-792-2933
Fax 713-794-4589

To: David Hui 10/02/2017
From: Babajide O. Sotunbo
CC: Julio A. Allo, Shana Callais, Vera J. DeLaCruz, Carol Hollinger, OPR Protocol Activations
MDACC Protocol ID #: PA17-0684
Protocol Title: Availability and Integration of Palliative Care United States Cancer Centers: An Update

Version: 00

Subject: Protocol PA17-0684 - Approved, Not Yet Activated, Not Human Subject Research

**IRB Approval Date:** 09/22/2017
**IRB Review Date:** 09/22/2017

On 09/22/2017 the Institutional Review Board 4
On 09/22/2017, the Institutional Review Board 4, chair or designee has reviewed this project and determined that it is not human subjects research and does not require IRB approval. Please note that any modifications to this project that may affect this determination, should be submitted to the IRB for approval prior to implementation.

It was noted that the protocol documents are satisfactory and in compliance with federal and institutional guidelines. It was also noted that risks to human subjects are minimal and that confidentiality of specimens or records/data will be maintained.

Please Note: This study is NOT YET ACTIVATED. No research related activites can begin on this protocol until it has been officially activated by OPR. You will receive a separate activation memo once all of the requirements have been met.

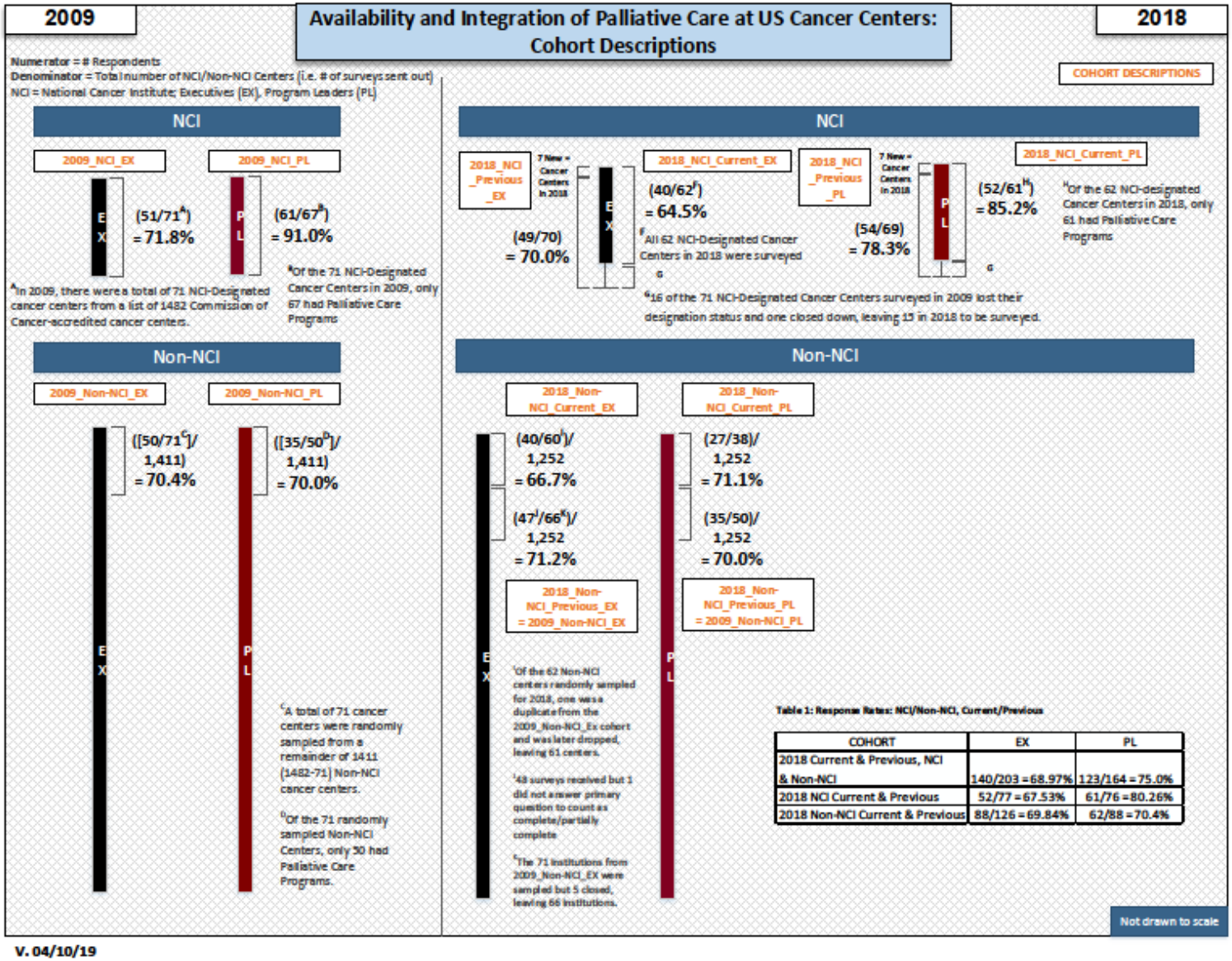
To request activation, send an email to 'OPR Protocol Activations'.

In keeping with the requirements outlined in 45CFR46.109(e) and 21CFR56.109(f), the IRB shall conduct continuing review of all protocols at intervals appropriate to the degree of risk, but not less than once per year.

In the event of any questions or concerns, please contact the sender of this message at (713) 792-2933.

Babajide O. Sotunbo 10/02/2017 11:24:55 AM

**Appendix 5**: Cohort Descriptions 2009-2018



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